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Younger Residents Through the Looking Glass: Perceptions of the Residential Experience of Non-Traditionally Aged Residents Living in the Long Term Care Setting

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YOUNGER RESIDENTS THROUGH THE LOOKING GLASS:
PERCEPTIONS OF THE RESIDENTIAL EXPERIENCE
OF NON-TRADITIONALLY AGED RESIDENTS LIVING IN THE
LONG TERM CARE SETTING

by

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DEDICATION

First: To my Andrew, who encouraged and listened as I “bemoaned my outcast fate” for the past four years. I love you more than I have words.... and I have a lot of words. Next: To Andy, Ivan, Mitch, and Ronnie... I am forever grateful to you all for sharing your time, your life stories, and your perceptions with me. Always: To my grandmother, Ruth Rebecca Renaas, who - along with her collection of aging and aged friends - literally picked me up off a doorstep, dusted me off, and reminded me “it’s not where you start, it’s where you finish.”

Andrew... this thing is finished. Let’s go!

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I am indebted to the Bentley Historical Library at the University of Michigan, for their generous support of this research and for assisting me as I worked my way through the archives.

Writing is a lonely thing, but I was not ever alone, because I had Andy, Jerry, JeongSuk, Mary, Stacy, Trang, Weizhou, and Tyrone. I had Jen, Diane, Jackie, Marcia, Leigh, Reva, David, and Susan. I had Clyde, Henry, and Millicent and, most importantly, I had my Andrew, my true North, always guiding me forward.

A family is a circle of people who love you... my circle is complete.

ABSTRACT

This embedded case study describes perceptions of the residential experience of non-traditionally aged persons (between the ages of 18-64), living in the Long Term Care (LTC) setting. Prior research identifies non-traditionally aged persons as the fastest growing group admitting to residential LTC care. Due to the complexity of need, younger residents may potentially languish in LTC for twenty, thirty, or more years. Non-traditionally aged residents currently comprise about 15% of the total residential LTC population; yet, little is known about this burgeoning group of younger persons, including how they perceive themselves as residents in LTC settings and how they are perceived by persons who work there.

Multiple sources of data were examined in this study, including a series of intensive interviews with four non-traditionally aged residents, focus groups with Certified Nurse Aides (CNAs) and Social Workers, examination of documents and artifacts, and observations. Findings were assessed for patterns and themes, and later analyzed through Cooley's (1902) Theory of the Looking Glass Self, which explores the interconnectedness of the self and the social environment. Findings from this study indicate that non-traditionally aged persons perceive their admission to the LTC setting as a result of capricious fate, while workers perceive that non-traditionally aged persons are responsible for their admission, due to risky behaviors and bad choices. Non-traditionally aged residents are aware of how they are perceived by others and strategize ways to improve the perceptions of staff. These strategic actions improve the delivery of services and establish

control within the institutional setting.

This study has several limitations, including the use of purposive sampling of Resident Participants, who share common characteristics of non-traditionally aged residents in other LTC settings, including permanent disability, low socio-economic status, social estrangement, and a history of mental illness. Additionally, the small sample of participants limits this study to analytical generalizations, through the comparisons of findings to existing theory. Further, this study limited perceptions of staff to only CNAs and Social Workers; yet, findings demonstrate the importance of social connections between younger residents and non-direct care Support staff, including persons who work in the departments of Dietary, Housekeeping, and Maintenance.

Additional research could provide a more comprehensive exploration of the residential experience of non-traditionally aged residents living in LTC, informing policies and practices that incorporate social components into the delivery of services, improving the LTC experience for persons who live and work within these settings.

Keywords: LTC, Long Term Care, non-traditionally aged, perceptions, social connections, younger residents

TABLE OF CONTENTS

DEDICATION	iii
ACKNOWLEDGEMENTS.....	iv
ABSTRACT	vi
LIST OF TABLES	x
LIST OF FIGURES.....	xi
CHAPTER 1: INTRODUCTION	1
CHAPTER 2: REVIEW OF THE LITERATURE.....	10
CHAPTER 3: METHODS OF STUDY	36
CHAPTER 4: FINDINGS.....	81
CHAPTER 5: DISCUSSION.....	141
REFERENCES	173
APPENDIX A: IRB APPROVAL	189
APPENDIX B: INFORMED CONSENT – RESIDENT PARTICIPANTS.....	191
APPENDIX C: INFORMED CONSENT – FOCUS GROUPS.....	195
APPENDIX D: RESEARCH TIMETABLE	198
APPENDIX E: RECRUITMENT FLYER FOR CNA FOCUS GROUP	199

APPENDIX F: PROTOCOL FOR SEMI-STRUCTURED INTERVIEWS WITH RESIDENT PARTICIPANTS	200
APPENDIX G: PRE-FOCUS GROUP SURVEYS – CNAs	203
APPENDIX H: FOCUS GROUP PROTOCOL – CNAs.....	206
APPENDIX I: PRE-FOCUS GROUP SURVEY – SOCIAL WORKERS	207
APPENDIX J: FOCUS GROUP PROTOCOL – SOCIAL WORKERS.....	210

LIST OF TABLES

Table 3.1 Study Criteria for Resident Participants	60
Table 3.2 Study Criteria for CNA Focus Group	62
Table 3.3 Study Criteria for Social Worker Focus Group	64
Table 4.1 Resident Participants – Demographic Information.....	94
Table 4.2 Focus Group Participants – Demographic Information.....	109

LIST OF FIGURES

Figure 3.1 Types of Data Sources.....	41
Figure 3.2 Embedded Units Within Golden Acres	50
Figure 3.3 Visual Representation of Research Methodology	54
Figure 4.1 Steps to the Entrance.....	85
Figure 4.2 Images from Leonard’s Room.....	90
Figure 4.3 A few of Mike’s pens	91
Figure 5.1 View from the nurses’ station, Leonard’s unit	123
Figure 5.2 Factors influencing actions and behaviors of non-traditionally aged residents in the LTC setting	143
Figure 5.3 Conceptual model of the perception feedback loop of perceptions and behaviors	152
Figure 5.4. Poor house road	154
Figure 5.5. Push to exit	170

CHAPTER 1

INTRODUCTION

I am not what I think I am. I am not what you think I am.

I am what I think you think I am.

- Charles Horton Cooley

This dissertation describes perceptions of the residential experience of non-traditionally aged persons, under the age of 65, living in the Long Term Care (LTC) setting. My interest in this group of persons inspired me to begin my doctoral journey, as I sought to discover more about non-traditionally aged residents and their experiences living in LTC. Though I have explored other interests during the past four years, all roads have led back to the same questions I had when I began. Who are these younger persons? How do they perceive life within the LTC setting?

I began thinking about the way younger residents experienced their world several years ago. I had resumed working in LTC, following my return to the United States. Although I had worked in various settings that provided care for seniors, I left that life when my husband and I were stationed overseas. When we returned almost three years later, I resumed my studies, and following completion of my master's degree program, I returned to LTC and was hired as a Licensed Master Social Worker for one of the largest LTC centers on the Eastern seaboard, where almost 300 residents permanently lived, and

and another 300 worked. I noticed significant changes, especially in the nursing home population, which had many younger residents, under the age of 65.

I was assigned two different units, and of *my* 88 residents, more than 20 were younger than 65. Most of the younger residents had experienced traumatic injuries, related to drug use and/or risky behaviors, including closed head injuries secondary to automobile or motorcycle accidents; cardio-vascular incidents related to drug use; and serious injuries secondary to gun-shot wounds. Most of the younger residents were estranged from their family of birth and had limited, if any, social networks.

Additionally, the majority experienced mental illness, which manifested in behaviors such as physical or verbal aggression, defiance, and yelling. All younger residents I encountered were poor and dependent on Medicaid, which funded the cost of their care. After a few months, I was promoted to the position of Psychiatric Liaison and became responsible for scheduling visits between residents and the contracted psychiatrist. As a result, I became acquainted with the additional five units of the home and found that most persons diagnosed with severe and persistent mental illness and personality disorders, such as schizophrenia, schizoaffective disorder, and bipolar disorder, were younger, with the older residents primarily diagnosed with mental illnesses related to dementia.

Younger residents were sometimes involved in altercations, usually with staff, who described younger residents as distracting, defiant, disruptive, and dangerous. Younger residents often received heavy medication, administered *pro re nata* (PRN) in response to these behaviors.

Facility policies, targeted for older persons, failed to address the complex needs of these younger residents who, due to the severity of need, would potentially remain in

LTC for decades, during years defined as their *prime of life* (Lachman, Teshale, & Agrigoroaei, 2015). Though I have left my role as a social worker in the LTC setting, my questions remain: Who are these younger persons? How do they perceive life within the LTC setting? And so, this work.

This chapter begins with a discussion about non-traditionally aged residents living in the LTC setting, outlining common characteristics of these persons. It discusses the problem statement, purpose of research, and research questions for this study. The chapter continues with a discussion of the theoretical foundation for this study, the relevance of this study to social work, and the relevance of this study to the existing body of scholarly works.

The Problem

Persons under the age of 65 represent the fastest-growing age group admitting to residential LTC, with about 5,000,000 persons under the age of 65 using some form of LTC services in the United States (Centers for Disease Control and Prevention, 2013; Family Caregiver Alliance, 2015). Currently, about 15% of all LTC residents in the U.S. are under the age of retirement, with this number expected to grow (Mulligan, 2016). Currently, little is known about the experience of younger residents living in LTC, including how best to meet their needs within the total institution (Harris-Kojetin, Sengupta, Park-Lee, & Valverde, 2013; World Health Organization (WHO), 2011). Unlike older residents who often enter institutionalized care due to chronic health conditions or injuries related to falls, non-traditionally aged residents, described by Harris-Kojetin and colleagues (2013) as persons between 18 and 64 years of age, primarily enter LTC due to physical impairments and permanent disabilities, related to

substance abuse, risky behaviors, and traumatic injuries (Singh, 2010).

Existing practices and procedures of LTC institutions are geared toward traditionally-aged residents, aged 65 years and older, and fail to personalize care for non-traditionally aged residents, who are predominantly male, of low socioeconomic status (SES), socially estranged, and living with a history of mental health disorders (Centers for Medicare and Medicaid Services, 2016; Hector, 2015; Singh, 2010; Society for Post-Acute and Long-Term Care Medicine, 2015).

The duration of care needed by the broad group of younger persons is often life-long, with the potential for non-traditionally aged residents to remain in care for two, three, or more decades (Singh, 2010; Society for Post-Acute and Long-Term Care Medicine, 2015). Non-traditionally aged residents are often admitted to LTC due to the absence of placement alternatives (Harris-Kojetin et al., 2013; Hector, 2015; Mulligan, 2016; Society for Post-Acute and Long-Term Care Medicine, 2015). In a report to the United States Census Bureau, Harris-Kojetin et al. (2013) reported that younger residents often enter LTC due to financial hardship, with most dependent upon financial support from a state-sponsored Medicaid system (Kaiser Family Foundation, 2017). Further, the absence of integrated services for persons living with chronic conditions, restrictions on home care access, and gaps in funding for home-based medical services contribute to the increasing number of LTC admissions for persons under the age of 65 (Harrington, Weiner, Ross, & Musumeci, 2017; Miller, 2011; Shapiro, 2010). Though most persons requiring care are assisted by family caregivers, Freedman and Spillman (2014) reported that social trends and financial strains limit the willingness and ability for family members to care for persons with permanent disabilities.

As a result, younger persons who experience the need for care and are estranged from family members, lack the physical, emotional, and financial supports needed to live in less restrictive settings (Miller, 2011).

Purpose of the Study

The purpose of this study is to gain a better understanding of younger residents by describing the perceptions of the residential experience of non-traditionally aged residents, living within the LTC setting.

Research Questions

The central research questions for this study are:

- RQ1: How does a non-traditionally aged resident perceive himself or herself, as a resident of the LTC setting?
- RQ2: How do workers (CNAs and Social Workers) in LTC perceive non-traditionally aged residents living in the LTC setting?
- RQ3: How do non-traditionally aged residents perceive the way they are perceived by LTC staff?

Assumptions

My study assumes that perceptions, of self or others, influence one's social reality, as explained by the Theory of the Looking Glass Self (Cooley, 1902) and the Theory of Disadvantage (Wolff & de-Shalit, 2007). Specifically, that:

- The reality of one's experience is based upon an intersection of one's own perceptions, the perceptions of others, and one's perception of the perception of others (Cooley, 1902) and that these perceptions influence the way one *fits* into a social context.

- Disadvantages experienced by persons are cumulative and cluster together, creating a state of chronic disadvantage, exacerbated through the perceptions of others (Wolff & de-Shalit, 2007).

Expectations/Perceptions

Understanding more about how younger residents in LTC settings perceive the residential experience can provide guidance in developing ways to address the complex needs of this population and promote ways for these non-traditionally aged residents to create and maintain social connections within the limitations of the institutionalized environment.

It is expected that social connections, whether actual or perceived, provide multiple supports for non-traditionally aged residents, including advocacy, greater access to services, and socio-emotional support.

Relevance

My study provides insight into the way non-traditionally aged residents are perceived within the LTC setting. Logical inferences, as described by Mitchell (1983), extend the findings from this study to the broader issue of how perceptions influence behaviors and documents, which serve as drivers of care in institutionalized settings. Though a considerable amount of literature exists regarding the influence of perceptions on patient (or resident) wellness (FitzGerald & Hurst, 2017; Hall et al., 2015; Joint Commission, Division of Healthcare Improvement, 2016; Pfister, Reeves, & Kneedler 2015), most studies focus on physicians, primarily in emergency or hospital settings (Dehon, Weiss, Faulconer, Hinton, & Sterling 2016; Joint Commission, Division of Healthcare Improvement, 2016). Though physicians play an important role in LTC, most

day-to-day care is provided through task-oriented direct care staff. Thus, perceptions of these staff members add to the understanding of the residential experience of non-traditionally aged persons living in this setting.

Approach and Propositions of This Study

My approach is primarily emic, in that I describe the residential experience of non-traditionally aged residents, through the perspective of persons who live, and work, in the LTC setting, through the words and experiences of the participants (Given, 2008; Pike, 1967). This bottom-up examination offers opportunities for a richer understanding about non-traditionally aged residents in this particular setting, using multiple units of analysis, including Resident Participants, Focus Groups, and Observational Data.

Though findings from this study are viewed through Cooley's (1902) Theory of the Looking Glass Self and allows for analytic generalizations to an existing theory, this analysis is used after the study completed and as a final part of the analysis, as opposed to a traditional etic approach, which would frame the process of analysis through a particular theory.

Yin (2018) presented case research as an appropriate method to gather information, especially where little is known. Case study also allows for close examination of individuals within a social context. This case study describes the understudied population of non-traditionally aged residents in the LTC setting, describing how they are perceived by themselves and others, within the social context of LTC.

My propositions about this study relate to the Theory of the Looking Glass Self (Cooley, 1902). Specifically, that:

- The reality of one's experience is based upon an intersection of one's own

perceptions, the perceptions of others, and one's perception of the perception of others (Cooley, 1902) and how these perceptions influence the way one *fits* into a social context.

- Disadvantages experienced by persons are cumulative and cluster together, creating a state of chronic disadvantage, exacerbated by the perceptions of others (Wolff & de-Shalit, 2007).
- Perceptions and behaviors are reciprocal, reflecting the intertwined relationship of the individual and the social environment (Cooley, 1902).

- **Overview of Research Design**

- To answer the research questions, this embedded case study examines the social
- world of non-traditionally aged residents, living in the LTC setting, where the phenomenon explored, and the social context are blurred and intertwined. This methodology reveals rich descriptions of phenomena and involves in-depth investigation of contemporary phenomena, within a real-world context (Yin, 2018). Kinchin and Francis (2017) outlined case study as a process of analyzing data from the bottom up, allowing the gathered data to describe phenomena that are unnoticed or undiscovered, dismissed or disregarded.
- Case study is unique to time, space, and place, offering a rich description of the lives of individuals often overlooked. Though this case study is not intended to be representative of all younger persons living in institutionalized care, nor provide statistical generalization to a population

(Gomm, Hammersley, & Foster, 2000; Yin, 2018), it does provide important findings, from this particular setting, to better understand this group of non-traditionally aged residents and possibly inform policies and

- procedures (Small, 2009; Yin, 2018).
- This research focuses on the perceptions of persons who live, and work, in the LTC setting, and provides a better understanding of the collective perceptions of - and about - non-traditionally aged residents who live within the social context of Long Term Care.

CHAPTER 2

REVIEW OF THE LITERATURE

The social self is simply any idea, or system of ideas, drawn from the communicative life.

- Charles Horton Cooley

This chapter will review classic and current literature related to non-traditionally aged persons living in LTC settings. The paucity of specific peer-reviewed literature on this subject supports the need for additional research about younger residents, who represent the largest growing group of persons entering LTC (Centers for Disease Control and Prevention, 2013; Family Caregiver Alliance, 2015). Most younger persons living in institutions of care lack socially supportive networks, live with multiple disadvantages, and face bias in residential healthcare settings (Barra & Singh Hernandez, 2018; Centers for Medicare and Medicaid, 2013).

Provider-to-patient bias is present in all healthcare settings and is a primary influence on the delivery of healthcare services, influencing patient safety and patient well-being (Gawande, 2010; Joint Commission, Division of Healthcare Improvement, 2016). Although perceptions and bias are present in all human interactions (Banaji & Greenwald, 2013), bias in healthcare, whether explicit or implicit, arises from the attitudes, perceptions, and expectations (APEs) of providers and is reinforced by social contexts, social expectations, and social mores (Banaji & Greenwald, 2013; English & Flaherty, 2019; Gawande, 2010; WHO, 2019).

The closed social setting of the nursing home influences the actions, behaviors, and perceptions of persons who live and work there.

The Long Term Care Setting

History of Institutionalized Care in the United States

Much of the history of institutionalized care in the United States echoes England's Poor Relief Act of 1601, which defined persons who could not contribute to society as burdens to it. Though there were distinctions between those deemed deserving of care and those deemed responsible for their own fate, limited resources were dispensed from the government to the impotent poor or their caregivers, according to a system that determined the worthiness of the individual.

Until the Industrial Revolution, most persons requiring care were provided for in the family home or in local community-based homes, supported by churches (Royal Commission on the Poor Laws and Relief of Distress, 1910). Those who were considered deformed, mentally ill, or violent were often sent away, along with persons who were impoverished or socially rejected. Although persons requiring care were sometimes cared for by county "nurses" or charitable organizations, many were sent to almshouses or work-farms, usually set in rural areas. Over time, persons were further separated, with those who had means, provided more options, sometimes taking the waters at sanitoriums or receiving care in elegant private homes. Worthy frail persons of less means were placed in rest homes, while incorrigible persons with criminal histories or severe mental illness were housed in prisons (Townsend, 1964).

The first nursing homes in the United States were opened around 1912, catering primarily to war widows and other indigent women who were "proper objects of relief"

(Townsend, 1964, p. 13). Some of these homes were supported by churches and charitable societies, but most were supported by families who privately paid for care. Over time, more homes were opened to offset overburdened public hospitals, who cared for the poor; however, many persons who were poor or mentally ill, continued to be relegated to work-farms or prisons. The Social Security Act of 1935 provided financial support for larger institutions, creating a further schism between large institutions supported by government funds and smaller providers that were supported through private pay.

The number of nursing homes grew over the next few decades, as care expanded, lifespans increased, and the medical model continued to emphasize deficits-based plans of care, resulting in larger and sicker populations residing in large institutions of care. Disruptive persons were often isolated in solitary conditions within the institution or otherwise restrained through chemical or physical means, sometimes for decades. Further funding was legislated in the 1960s through Medicare and Medicaid programming, which broadened public funding for skilled nursing services.

Omnibus Budget Reconciliation Act of 1987

The Omnibus Budget Reconciliation Act of 1987 (OBRA) reformed nursing home and residential care, rewriting guidelines and oversight to regulate different levels of care, with the goals of implementing resident's rights, including opportunities for persons to live in the least restrictive environment of care (Omnibus Reconciliation Act (OBRA), 1987). Kelly (1989) noted that OBRA established minimum standards of practice for any facility receiving public funding, implementing: resident access to dietary, nursing, pharmaceutical, recreational, rehabilitative, and social services; increased training and

testing of direct care workers; establishment of national registries for direct care workers; initial and periodic assessments of residents; and access to a full-time social worker, with one social worker for every 120 residents. Despite care reforms established through this legislation, many centers of LTC fail to meet these minimum standards.

Long Term Care Today

The term “Long Term Care” may be defined as care and supervision, provided to persons, of any age, who can no longer provide daily tasks due to chronic disease, injury, or trauma. These activities of daily living (ADLs) include: ambulating, bathing, eating, dressing, grooming, toileting, and transferring (U.S. Department of Health and Human Services (DHHS), 2017). Data from the Centers for Disease Control (CDC) and Prevention and the U. S. Department of Health and Human Services (DHHS) demonstrated that over 70% of all Americans will, at some point, require LTC services, which are usually provided in one’s home, by family members; however, may be provided by persons other than family, including persons who are trained to provide these services to others (DHHS, 2017; Harris-Kojetin et al., 2013). Some persons receive out-of-home, residential LTC, due to lack of access to services, the absence of social support, financial burden, or the level of care required.

Residential LTC is provided in a variety of settings, which vary according to levels of care. Assisted Living Facilities provide help with medication and personal care for individuals requiring some assistance with ADLs; Board and Care Homes provide limited housekeeping, laundry, nutrition, and personal care for more independent persons; Continuing Care Retirement Communities provide a continuum of care, allowing residents to age-in-place; Memory Care Homes specialize in care for persons

living with Alzheimer's Disease or other dementias; and Skilled Nursing Facilities provide 24-hour care for persons unable to perform ADLs (National Institute on Aging, 2017).

Historically, most LTC settings have catered to persons over the age of retirement; however, residential options that offer services *a la carte* have expanded over the past decades, allowing more persons to live in less-restrictive levels of care. Most non-skilled settings are billed as private pay, and though some accept Medicaid waivers for care, public insurance and funding sources do not pay for the cost of housing (American Council on Aging, 2019). As a result, persons who have fewer financial means of support are more likely to live in Skilled Nursing Facilities, regardless of age (Aschbrenner, Grabowski, Shubing, Bartels, & Mor, 2011).

About 5,000,000 million persons receive some form of LTC, both in home and out-of-home. The expansion of out-of-home options that arose after OBRA has led to a decrease in the number of persons living in institutionalized long-term residential settings, with reports to the National Investment Center for Seniors Housing and Care noting closings of nursing homes at an average rate of almost 300 per year, since 1995 (National Investment Center for Seniors Housing and Care (NIC), 2019; Span, 2019). Currently, about 1.5 million persons live in nursing homes in the United States, with about 85% of residents over the age of 65 (Centers for Disease Control and Prevention, 2016). Long Term Care residential settings offer in-patient, residential skilled care for persons requiring assistance with ADLs. Employees who provide physical or social care must be licensed or certified, by state boards, to assist with ADLs. Although guidelines vary from state to state, federal and state policies outline that most persons admitted to

residential LTC require an advanced level of care and assistance with, at least, three ADLs (Centers for Medicare and Medicaid Services, 2018).

Bias in Healthcare

Bias against vulnerable populations is common in healthcare, contributing to over-treatment, under-treatment, and discrimination against groups determined as the undeserving poor (Snowden & Graaf, 2019). A 2016 report to the Joint Commission noted that unconscious bias influences the way providers interpret and perceive information about those who seek care, influencing “differential treatment of patients by race, gender, weight, age, language, income, and insurance status” (Joint Commission, Division of Healthcare Improvement, 2016, para. 3).

Snowden and Graaf (2019) emphasized that persons perceived as *non-deserving* encounter bias that they are responsible for their poor health and “should be able to work for employer-sponsored health coverage or otherwise pay for their own healthcare” (p. 9). This categorization of residents, informed by the personal APEs caregivers hold, is reinforced by the social environment where care is requested and rendered (Gawande, 2010). Persons who fall outside traditional norms and expectations are subject to bias, including ageism, whether directed toward older or younger residents (Burgess, Warren, Phelan, Dovidio, & van Ryn, 2010; Butler, 1969; Cirillo, 2018).

Perceptions

All bias is based on perception. Banaji and Greenwald (2013) asserted that perceptions are the result of filtering information-in-context, with perceptions being influenced by social situations and places. Bias is prejudice toward or against something, based upon perceptions and is a result of implicit and explicit beliefs and values

individuals hold as true (Banaji & Greenwald, 2013). Though perceptions maintain separations between *us* and *them*, bias – whether implicit or explicit – leads to action for or against an individual or group.

Jacoby-Senhor, Sinclair, and Smith (2015) described this *othering* as a result of *implicit homophily*, where individuals who are members of a like group separate individuals they perceive as different from the groups to which they belong, or the groups recognized as familiar. Banaji and Greenwald (2013) noted this insider-outsider bias as a mental sifting of persons as worthy or unworthy. Persons perceived as worthy are those who we know, those who we recognize, those who are familiar. Persons we don't know, recognize, or find familiar are considered unworthy outsiders and we take action to remain separated from them, with these actions informed by the attitudes, perceptions, and expectations that are refined by the social environment in which persons operate. Simply put: those who are most like us, we are most likely to like.

Banaji and Greenwald (2013) explained that most of this sifting takes place implicitly and our failure to recognize implicit bias is a *blindspot* of perception. Perceptions are evaluations of observable data, influenced by social context, with meaning-making an outcome of the intertwined relationship between the social environment and individuals who live and work within that space (Banaji & Greenwald, 2013; Cooley, 1902).

Non-traditionally Aged Residents

Advances in medical care and technology have extended the lifespan of most persons, many of whom will require institutional medical support as they age (Freedman & Spillman, 2014; Jacobsen, Kent, Lee, & Mather, 2011); yet, the need for this care is

not restricted to those who are older. The growing phenomenon of non-traditionally aged residents has been noted as a global problem, especially among first world nations with less collectivist cultures and less multigenerational living situations (WHO, 2011).

Current estimates note about 15% of persons receiving residential-based LTC in the United States as younger than 65 years of age, with this number expected to grow, especially among persons living with multiple disadvantages, including permanent disability, low SES, social estrangement, and mental illness (Centers for Medicare and Medicaid Services, 2016; Centers for Medicare and Medicaid Services, 2018).

Disadvantages experienced by non-traditionally aged residents living in LTC settings separate them from the larger social world, with many of these persons languishing in care for most of their adult life. These disadvantages contribute to what Goffman (1961) described as a categorization by care providers. These categorizations are the result of explicit and implicit bias that all workers hold, based upon their APEs (Banaji & Greenwald, 2013; English and Flaherty, 2019). Robert Butler (1969) first described *ageism* as a form of bigotry against an age class. Though ageism is primarily defined as bias against older persons, discrimination directed toward any age group is a form of ageism. Persons under the age of 65, living in LTC settings, are situated in spaces where they are segregated by perceptions reinforced by the social environment in which they live (Butler, 1969; Goffman, 1961; Trattner, 1999).

Blair, Steiner, and Havranek (2011) asserted that biased perceptions are persistent among healthcare providers, influencing the delivery of services. A process of victim blaming is noted among providers who determine poor health and wellness on choices made by an individual (Daker-White et al., 2015). These negative perceptions are framed

by existing attitudes and perceptions providers hold of patients that label accident or injury as a result of patient choice (Daker-White et al., 2015; Ewert, 2013). Such bias, whether explicit or implicit informs perceptions and actions of persons who live and work within the total institution and are present in the everyday interactions between staff and residents, despite provider denials of bias (Banaji & Greenwald, 2013).

Clusterings of Disadvantage

Wolff and de-Shalit (2007) described multiple limitations and stressors experienced by persons as *clusterings* of disadvantage, which “reinforce pattern of entrenched privilege and disadvantage, widening gaps” between what people have and what people need (p. 186). Non-traditionally aged residents living in the LTC setting experience multiple disadvantages, including restrictions regarding personal autonomy (Hector, 2016; Rosen, Pillemer, & Lachs, 2008). The lack of options regarding food preferences, independence, life-style choices, on-going rehabilitative care, privacy, sexual expression, socio-emotional support, and transportation impacts all residents, but may be especially difficult for younger persons living in a system geared toward older persons struggling with chronic conditions (including dementias) and end-of-life issues.

The practices and procedures of LTC focus, almost exclusively, on the needs of older residents. Indeed, Bowen and Zimmerman (2008) determined the purpose of LTC as providing care to *older persons* (emphasis, mine) living with "recent impairments in their activity of daily living, disabilities or advanced chronic conditions including dementia; and people who are approaching the end of life" (p. 1).

Multiple disadvantages may be present prior to admission as well, with non-traditionally aged residents experiencing a clustering of disadvantages – permanent

disability, social estrangement, mental illness, and poverty, which cluster together, limiting living options for non-traditionally aged persons. Cumulative disadvantages create cumulative stressors that contribute to poor physical and emotional health, including permanent disability and mental illness (Robertson, Beveridge, & Bromley, 2017).

Permanent Disability

A permanent disability is a physical or mental impairment that prevents a person from full and independent participation in life. It is often a result of a traumatic injury or physical/biochemical limitation present at birth (Social Security Disability Resource Center, n.d.). Although older residents enter care primarily due to chronic diseases, non-traditionally aged persons are primarily permanently admitted to nursing homes following trauma or accident (Centers for Medicare and Medicaid, 2016). These traumatic events create life-changing effects that prevent independent movement or function.

Non-traditionally aged residents are often admitted following car accidents, acts of violence, or drug-related events (Centers for Medicare and Medicaid, 2016). Persons living with permanent disabilities are often dependent on others to assist the individual with ADLs. Additionally, persons who are under-insured or un-insured often receive less specialized care and admit to the nursing home directly from the hospital, as they may not qualify for funded rehabilitative services (Grebla, Keohane, Lee, Lipsitz, Rahman, & Trivedi (2015).

Social Estrangement

Younger adults who have histories with risky behaviors and substance use, often

experience social estrangement from family and friends. Laws, Ellerbeck, Rodrigues, Simmons, and Ansell (2017) confirmed that “social rejection threatens one of the most fundamental of human needs: the need to belong and experience social bonds” (p. 820).

Family estrangement, institutionalized living situations, and the absence of social networks can exacerbate chronic physical conditions and existing mental health disorders experienced by non-traditionally aged residents, further marginalizing and isolating these disadvantaged persons (Hector, 2015; Rosen, Pillemer, & Lachs, 2008; Souder & Sullivan, 2003).

Wolff and de-Shalit (2007) argued that *clusterings* of disadvantage become set by time and place, with marginalization, loneliness, and social isolation contributing to poor outcomes (Lubben, Girona, Sabbath, Kong, & Johnson, 2015). Laws et al. (2017) presented the cyclical influence of social estrangement on risky behaviors, which may lead to further social rejection by family and close friends, promoting persons to participate in more intense risky behaviors as a form of comfort, further distancing persons from the protective aspects found in social supports.

Mental Illness

While OBRA legislated improvements regarding quality of care for patients, it also outlined legislation regarding the deinstitutionalization of persons living with mental illness, allowing persons to seek care outside of facilities and self-administer medications, essentially ending federal funding for residential mental health. As a result, persons living with severe mental health issues were left with fewer options for care, including housing. The Olmstead Act of 1999 established mental illness as a disability, which opened housing options for persons living with severe mental illness, including

admission to residential nursing care.

Kaldy (2018) noted that nursing facilities are often the only long-term option of care for individuals living with both mental and physical disability, many of whom tend to be younger persons with histories of alcohol or drug use and/or misuse. Many younger residents have a history of mental health disorders and exhibit behaviors associated with anger, frustration, and anxiety (Centers for Medicare and Medicaid Services, 2016). This influences the perception of non-traditionally aged residents, by staff and others, as creating disruption and safety concerns for staff and residents who are frail (Souder & O’Sullivan, 2003). Souder and O’Sullivan (2003) described *disruptive* behaviors as “socially unacceptable or isolating, observable actions” such as physical or verbal aggressiveness, defiance, demands, or abusive behaviors (p. 31). Such behaviors may be symptomatic of mental illness but perceived as intentional actions, contributing to more negative perceptions regarding the population of non-traditionally aged residents (FitzGerald & Hurst, 2017; Souder & O’Sullivan, 2003).

While federal law mandates pre-admission mental health screenings for persons with mental health histories admitted to residential LTC, there are no federal mandates for staff training regarding severe mental illnesses, including recommendations for de-escalation techniques and responses. Additionally, training requirements for direct care staff varies from state to state (Office of the Inspector General, 2005; OBRA, 1987). Healthcare providers often consider younger persons as unlikely to comply with healthcare recommendations, particularly if the resident has a history of repeated admissions to, and discharge from, hospitals, rehabilitation centers, and skilled care facilities (Brownie & Nancarrow, 2013). FitzGerald and Hurst (2017) declared that

residents exhibiting behaviors and symptoms related to mental illness experience bias from direct care are staff, which is “likely to have a negative impact on an already disadvantaged group” (p. 2).

These perceptions contribute to disparities of care, stigmatization, and continued disadvantage for non-traditionally aged residents (Dehon et al., 2017; Pfister et al., 2015; Wolff & de-Shalit, 2007). Shin and Aboudan (2018) emphasized that symptoms related to mental illness may be exacerbated by trauma and delirium, particularly for newly admitted residents. Intensity of symptoms can influence assessments and other forms of documentation, leading to mistakes in records and response, increasing personal bias about residents labeled as unstable or unpredictable (English & Flaherty, 2019).

Poverty

Poverty paves the road of disadvantage and is the main determinant of poor health (Adler et al., 2016; Adler & Newman, 2002; Office of Disease Prevention and Health Promotion, 2019). Low SES has long been noted as a social determinant of care for vulnerable populations. The Office of Disease Prevention and Health Promotion (2019) has identified poverty as a target for their HealthyPeople2020 campaign, noting SES as a contributing factor for health and, particularly for persons in young and middle adulthood, affecting the ability for persons to access and secure stable housing, healthy food, and preventative healthcare that offsets risk for morbidity and mortality.

Living with low SES determines choices of care, as persons that are underinsured or uninsured often have financial limitations that prevent access to community or home-based care, following discharge from acute or emergency medical care. Skilled residential LTC facilities are funded primarily through state and government sources,

including Medicare, Medicaid, and state-based Quality Assessment Programs, with almost 60% of financial support provided through federal funds (Centers for Medicare and Medicaid, 2018). Most persons under the age of 65 are usually ineligible for Medicare (due to age) and Supplemental Security Income (due to placement in a nursing facility following trauma (Social Security Administration, 2019). Additionally, younger residents often fail to qualify for in-patient rehabilitative services that are funded through Medicare. For many younger persons who admit to LTC from emergency rooms or hospitals, admission to care is accomplished through application to state-based funding programs, such as Medicaid or MediCal. Admission to the nursing home under a Medicaid-pending status often offers the sole means to financially secure care, offsetting economic disadvantages experienced prior to admission (Adler & Newman, 2002).

Gaps in the Literature

There is a dearth of current research on non-traditionally aged residents. Most existing reports focus on concerns regarding the appropriateness of placement of younger persons in LTC settings that primarily serve older persons living with chronic conditions, including dementias (Office of the Inspector General, Department of Health and Human Service, 2001; Office of the Inspector General, Department of Health and Human Service, 2007; Society for Post-Acute and Long-Term Care Medicine, 2015). Though popular media occasionally features accounts of non-traditionally aged LTC residents, there is an alarming lack of research about this growing population.

The person-centered focus is considered a gold-standard of care; however, skilled care is often standardized and fails to incorporate individual needs into everyday practices in institutional settings (American Geriatrics Society Expert Panel on Person-

Centered Care, 2015; Clissett, Porock, Harwood, & Gladman, 2013). Social connections inform and respond to perceptions and action, with perceptions and action guided by the social context. Clissett, Porock, Harwood, and Gladman (2013) noted social connections between patients and caregivers as central to person-centered care, adding that organizational ethos contributes to the way perceptions and actions play out in the healthcare environment.

Research is needed to describe the residential experience of non-traditionally aged persons who live in LTC settings, including how perceptions of staff influence the delivery of services for younger residents. To understand more about the residential experience of a non-traditionally aged resident living in the LTC setting, I conducted a pilot study in Summer 2018.

Leonard's Life: A Pilot Study

My pilot study was supervised by Naomi Farber, PhD and approved through the Institutional Review Board of the University of South Carolina. "Leonard's Life: An Examination of a Life Lived in Long Term Care" was an exploratory case study of a non-traditionally aged resident, living in the LTC setting. Leonard experienced multiple physical conditions related to cerebral palsy, including difficulties with speech and swallowing, lack of fine motor skills, exaggerated and spastic gross motor movement, incontinence, and the inability to ambulate without assistance. Leonard was abandoned at the nursing home, at the age of 18, and has lived there for 44 years. I cannot think of anyone who could teach me more about the perception of residential experience among non-traditionally aged persons, living in the LTC setting than Leonard.

Over the course of the summer, I conducted six intensive interviews with

Leonard. The findings from my pilot study shaped my research questions and my quest to describe how younger residents perceive their lives, and how others perceive them, as well. I wanted to find out more about the way Leonard saw himself as a resident of a nursing home. How did he feel about living there? How did he socially connect with others? What did he think others thought of him, as a person who had spent the whole of his adult life in this setting? What could he teach me about his life and the life of other younger persons who lived in the LTC setting?

Findings from the pilot revealed that Leonard did not long for what he called “a normal life.” He did not miss having children or a career, which he acknowledged that most people his age experienced. He did not miss having a romantic relationship. He did not bemoan his physical limitations and, instead, stated: “I went to a nursing home. That’s what happened. I can’t change that. It hasn’t been terrible; in fact, it is better than my own family. I roll with the punches. This is what it is.” Leonard shared that he felt welcomed among most of the staff and he noted social connections with several support staff, including Maintenance workers who frequently helped him with his computer and phone. He also felt close to several support staff members who worked for Rehabilitative Services.

I go there every day, first thing. Right after I get dressed, I grab the paper and drive to Rehab. I get there before anyone else and we sit and talk. I sit and read the sports page and watch CNN. Last month, they even had a birthday party for me, my first one ever.

Leonard did not have the same kind of interactions with Care staff, who he labelled as “dumb” or “lazy.” “Most of them are only here for a paycheck, they just do what they have to do and move on. They don’t have time for me, and I don’t have time for them.” Both Leonard and care staff reported their interactions as perfunctory, with some CNAs describing Leonard as “demanding,” “rude,” and “spoiled.”. For his part, Leonard shared that he depended on the Care staff to take care of him, “but that’s it. If I need something, I go across the hall” (to the Administrative Offices or the Rehabilitation Center).

My experiences conducting this pilot benefitted my work in many ways. A broad benefit was the establishment of a trusted relationship between me and persons who worked at the nursing home. There were multiple gatekeepers at this setting and all of them seemed – at least initially – concerned with the purpose of my pilot study. Some workers expressed suspicion that I would report “anything wrong” and workers were careful not to speak to each other in front of me. Over the course of the summer, I worked to establish trusting relationships with care and support staff, making efforts to assure workers that my purpose was to tell Leonard’s story. This investment was crucial for my dissertation work and allowed me a level of access that may not have been granted without it. My pilot work also allowed me to identify informal leaders among the staff, who promoted the Focus Groups with CNAs and Social Workers. These leaders accessed old records, scheduled quiet places for me to work, supported access to electronic documents, and assured fellow staff that I was “o.k.”

My pilot work provided me with real world experience in guiding interviews. Although I had prior experience conducting interviews, I found it much harder to guide

interviews with Leonard, as I was familiar with him, and at first, our interviews were merely conversational. Over time, I learned how to create a protocol to target what I wanted to know and how to stick to it. Perhaps, most importantly, the pilot study allowed me to take on a different role in the nursing home, where people knew me as a former worker. The pilot study built a bridge between my former role as a worker and my present role as a researcher.

My pilot study also confirmed that further investigation of younger residents would provide a better understanding of how they perceive their world and their interactions with others, and informed the research questions for my dissertation, discussed in Chapter One, and revisited, below.

Research Questions

The central research questions for this study are:

RQ1: How does a non-traditionally aged resident perceive himself or herself, as a resident of the LTC setting?

RQ2: How do workers in LTC perceive non-traditionally aged residents living in the LTC setting?

RQ3: How do non-traditionally aged residents perceive the way they are perceived by LTC staff?

Definitions of Terms

Nursing home terminology often uses short-cuts and acronyms that are specific to healthcare settings. The following list is not inclusive of all terminology used in this study; however, it attempts to ease understanding for the reader. Additional terms will be defined throughout the body of this work.

<i>Activities of daily living (ADLs)</i>	Activities required to maintain health and safety – eating, bathing, dressing, grooming, toileting, transferring, and managing continence
<i>Administrative staff</i>	LTC employees that supervise or directly support persons who supervise staff (Administrator, Director of Nursing, Director of Social Services, Marketing Representatives)
<i>APEs</i>	Attitudes, Perceptions, and Expectations
<i>Care staff</i>	LTC employees charged with assessing and/or providing ADLs to LTC residents (CNAs, nurses, Social Workers)
<i>Clusterings of disadvantage:</i>	Multiple limitations and stressors, experienced by individuals, which “reinforce pattern of entrenched privilege and disadvantage, widening gaps” (Wolff & de-Shalit, 2007, p. 186)
<i>Delivery of services</i>	The way in which care is rendered or tasks are provided by staff
<i>Disruptive behaviors</i>	“...socially unacceptable or isolating observable actions” such as physical or

verbal aggressiveness, defiance, demands, or abusive behaviors (Souder & O’Sullivan, 2003, p. 31).

Long-term Care (LTC) setting

Residential institution, staffed by licensed or certified health care workers, who provide 24-hour skilled assistance with ADLs

Non-traditionally aged resident

Person admitted to institutions of care who are between 18-64 years of age

PASRR

Preadmission Screening and Resident Review, mandated upon admission for persons having a history of mental illness. PASRR is designed to identify persons who may present a danger to the nursing home environment (PASRR is required for any facility that receives public funding)

Perceptions

One’s understanding of truth, based upon impressions, experiences, and *how things seem*

Pro re nada (PRN)

“As needed.” In this study, PRN refers to prescribed medication that is dispensed on an as needed basis, usually in response to behaviors associated with acute symptoms of mental illness

<i>Resident</i>	Person permanently admitted to an institution of care
<i>Risky behavior</i>	Voluntary participation in behaviors that are perceived to be unsafe, such as experimenting with illicit drugs, unprotected sex, and reckless driving
<i>Social connectedness</i>	Voluntary social interactions between persons
<i>Social networks</i>	Social communities to which a person belongs, familial or non-familial
<i>Social estrangement</i>	Lack or limitation of one's social network, familial or non-familial. For this study, social estrangement refers to a lack of connection with persons outside of the LTC setting.
<i>Social isolation</i>	Absence of social connection between an individual and others, within a social environment
<i>Support staff</i>	LTC employees who are charged with tasks that support the nursing home environment (Dietary staff, Housekeepers, Laundry workers, Maintenance workers)

Traditionally aged resident

Permanently admitted person, who is 65 years of age, or older, and residing in an institutional setting

Theoretical Framework

The purpose of case study is not to garner statistical generalized findings to a target population. Rather, case studies explore, explain, and describe unique phenomena to gain rich understandings of phenomena within real-world contexts, often comparing findings to existing theoretical frameworks and propositions. Case studies help answer questions of how and why (Given 2008; Pike 1967; Yin, 2018). In the case of this research: How is the residential experience of non-traditionally aged residents perceived by persons who live and work within LTC settings?

The rich descriptions offered through case studies are supported by what Kinchin and Francis (2017) outlined as a process of analyzing data from the bottom up, allowing the gathered data to describe phenomena that has often been unnoticed or undiscovered, dismissed or disregarded. This approach provides better opportunities for understanding the collective perspectives and experiences of persons within a social setting by using the direct words of participants and direct observations, triangulating multiple units of analysis, and analyzing findings through a process of coding to reveal patterns and themes (Given, 2008, Pike, 1967).

Developmental Theory

Some of the assumptions for this study are drawn from Erikson's 1950 psychosocial developmental stage theory, reflecting individual and social expectations for persons in young adulthood and middle adulthood, including how non-traditionally aged

institutionalized persons confront developmental crises. Erikson asserted that persons worked through eight developmental stages, from infancy to old age. During each stage, the individual faces a crisis related to the stage of development. Resolving of the crisis allows the individual to successfully continue to the next stage; however, failure to resolve the crisis creates a stagnation of development, impairing psychological growth.

Non-traditionally aged residents fall into the sixth (Young Adulthood) and seventh (Middle Adulthood) stage of Erikson's psychosocial developmental theory.

Young adulthood. The sixth stage of Erikson's developmental theory is Young Adulthood, occurring approximately between the ages of 21 and 39 years of age. This stage focuses on relationships and love, with young adults facing decisions about establishing relationships and families. Erikson described the developmental crisis of Young Adulthood as "Intimacy vs. Isolation," with persons who successfully negotiate this stage of development, gaining the virtue of Love (Erikson, 1950/1963).

Middle adulthood. The seventh stage is Middle Adulthood, occurring approximately between the ages of 40-65 years of age. This stage focuses on legacy and contributing to society, with middle adults facing issues of changes in family and career, as children leave home and individuals prepare to retire from work. Erikson noted the developmental crisis of Middle Adulthood as "Generativity vs. Stagnation," with persons who successfully cope in middle adulthood finding new purposes in life as they age, gaining the virtue of Care (Erikson, 1950/1963).

The Theory of Disadvantage

Assumptions are also informed by Wolff and de-Shalit's 2007 Theory of Disadvantage, which asserts that vulnerable persons experience multiple disadvantages,

created and maintained by social barriers. The plurality of Disadvantage limits one's control over life; bodily health; bodily integrity; affiliation; the environment; and sense, imagination, and thought.

Wolff and de-Shalit (2007) also noted that Disadvantage is not explained by the lack of things, but by the lack of access to the potential of having things, which is determined by social and political barriers. The experience of life-long barriers to wellness burdens disadvantaged persons with a cumulative allostatic load that creates physical manifestations of stress (Robertson, Beveridge, & Bromley, 2017).

The Theory of the Looking Glass Self

Charles Horton Cooley introduced his Theory of the Looking Glass Self in his 1902 book, *Human Nature and the Social Order*, where he outlined the symbiotic relationship of the individual and society. Cooley (1902) asserted that the self was not a response to one's social context, but a result of reflexive interplay with it, involving a "reflexive triumvirate" of interaction of impressions, perceptions, and actions (Jacobs, 2006, p. 193). Though this study primarily uses an emic approach that describes perspectives of participants through their own words and experiences, it includes a final etic analysis, allowing for analytical generalization through the comparison of findings to existing theory.

Cooley's work focused on the dynamic and intertwined nature of perceptions and the social environment. To develop an analytical generalization, findings from this study are analyzed through Cooley's 1902 Theory of the Looking Glass Self, which asserts that a person's reality is created through:

- 1.) The way one perceives oneself,

- 2.) The way one is perceived by others, and
- 3.) The way one perceives how they are perceived by others.

This dual approach is used to answer the research questions through what Cooley described as an *organic view*, defining the individual and society as interconnected parts of the same whole, where the “individual is not separate from the human whole, but a living member of it” (Cooley, 1902, p. 35).

Summary

Disadvantages experienced by non-traditionally aged residents living in LTC settings separate them from the larger social world, with many of these persons languishing in care for most of their adult life. These disadvantages contribute to what Goffman (1961) described as a categorization by care providers. These categorizations are the result of bias that all workers hold, based upon APEs (Banaji & Greenwald, 2013; English and Flaherty, 2019). Adler and Newman (2002) outlined that bias contributes to a culture of victim-blaming, where the behaviors of patients are viewed as the primary reason for ill health.

Though Gawande (2010) and Snowden and Graaf (2019) presented multiple examples of physician-based bias, provider bias is present across various domains of care, including residential environments where care is provided primarily through direct care staff, influenced by perceptions and the social context that inform bias regarding individuals presenting for care.

Despite the influence of worker perceptions on resident care, no significant studies exist regarding younger LTC residents and those that do, focus on the appropriate placement of non-traditionally aged residents within the LTC setting. Understanding

more about the perceptions of non-traditionally aged residents will add to the paucity of literature regarding this growing group of non-traditionally aged persons living in LTC settings.

This case study demonstrates that each person's "experience ought to be worth something to the community from which he drew it" (Riis, 1890, p. 2). My study demonstrates the worth of non-traditionally aged residents through the examination of perspectives of the residential experience, within the community of the LTC setting. It describes perceptions of the non-traditionally aged residents' social world and those who interact with them. It provides a close examination and deeper understanding of this burgeoning group, including how they perceive themselves and are perceived by others.

This embedded case study provides a close examination of individuals within a social context and is particularly relevant for this particular group, in this particular setting, providing a better understanding of younger residents, making more visible those who live in the margins of care.

CHAPTER 3

METHODS OF STUDY

*There is no way to penetrate the surface of life but by attacking it
earnestly at a particular point.*

- Charles Horton Cooley

Prior to the initiation of this study, I applied for approval for research with human subjects through the Institutional Review Board (IRB) of the University of South Carolina. This study met all rules, regulations, and requirements, as established by the IRB, and was granted exempt status (Appendix A).

There were limited anticipated risks to the participants of this study; however, a statement of risk was reviewed with each participant, via Informed Consent, including possible risks and benefits associated with the study. The discussion of Informed Consent - Resident Participants (Appendix B) took place during the first meeting, prior to the first interview. Informed Consent – Focus Groups (Appendix C) took place at the beginning of each Focus Group session, prior to initiating the Focus Group. I allowed time at these first meetings to clarify any information about the study and provided participants with copies of signed documentation of Informed Consent, including contact information for myself, my research supervisor, and the university. Due to the sensitive nature of some of the interview questions with Resident Participants, Informed Consent for Resident Participants included permission to release information to facility Social Workers and the area Ombudsman.

I provided documentation of Informed Consent to each Resident Participants’

respective Social Worker, along with an interview schedule. I also informed the Social Workers of any discussion topics that could potentially cause upset or distress for the Resident Participant(s). Additionally, I informed the designated regional Ombudsman of the study and provided a copy of the approved IRB.

Introduction

This chapter explains my decisions regarding research design and methods for this study, including the use of an embedded case study approach. Yin (2018) asserted that the case study method is appropriate for gathering deep understanding of real-world experiences, especially when the boundaries between the phenomena and the social context are unclear. This embedded case study is bounded by the LTC setting and describes the residential experience of non-traditionally aged residents from multiple perspectives of persons who live and work within the particular social context.

The topic for this study arose from my personal and professional experiences in LTC facilities and was conducted to examine the following questions, which are repeated, below.

Research Questions

- RQ1: What are the perceptions of self for a non-traditionally aged resident in the LTC setting?
- RQ2: What are the perceptions that staff (CNAs and Social Workers) have of non-traditionally aged residents living in the LTC setting?
- RQ3: How does a non-traditionally aged resident perceive the way they are perceived by LTC staff?

Case Study

Case study examines phenomena within a real-world context. Shalveson and Towne (2003) explained that case studies are appropriate for descriptive or explanatory studies, where other methods may fail to capture intricacies and particularities. Bromley (1986) noted case study research as involving a process of discovery, including the collection of data in natural settings. The case study method of research employs up-close examinations to develop rich, thick descriptions of persons and/or phenomena in the life world context, including the thoughts and actions of persons who occupy space within a social setting and the meanings, created and maintained within this same space (Husserl, 1970). O'Toole and Were presented these organic studies of person-in-space as opportunities for researchers to "gain new perspectives on the social world" (p. 616).

Though concerns may arise regarding the rigor of qualitative case study, Yin (2018) asserted that systematic methods, including the use of multiple data points, addresses questions regarding validity and rigor. This case study describes findings from multiple units of analysis, allowing for triangulation of collected data, and employs both emic and etic approaches to describe the residential experience of non-traditionally aged residents, living in the LTC setting. Case study is more than narrative vignettes of the lives of participants. It involves close observation from multiple points of data, using an iterative method of analysis to examine the social construction of meaning (Gaikwad, 2017; O'Toole & Were, 2008). Case study methodology presents opportunities for researchers to engage in creative methodologies; however, this flexibility presents concerns about rigor and the ability to apply findings to the broader population (Gaikwad, 2017; Lewis & Nicholls, 2014; Yin, 2018).

Trustworthiness and Validity in Case Study

Pursuing construct validity in case study research is one way to generate trustworthiness and rigor in the research process. Construct validity assures that the interpretations during coding and analysis do not merely confirm findings that the researcher anticipated *a priori*. The research process is not limited to confirmation or disconfirmation of research propositions or theories; rather, the researcher pursues alternative analytical and theoretical explanations during coding and analysis, including the representation of outliers in the representation of findings (Lather, 2007). Additionally, researcher reflexivity is an essential part of this process. As Lather (2007) explained:

Construct validity must be dealt with in ways that recognize its roots in theory construction (Cronbach & Meehl, 1955). Emancipatory social theory requires a ceaseless confrontation with the experiences of people in their daily lives in order to stymie the tendency to theoretical imposition which is inherent in theoretically guided empirical work. *A systematized reflexivity*, which gives some indication of how a priori theory has been changed by the logic of the data, becomes essential in establishing construct validity in ways that will contribute to the growth of illuminating and change-enhancing social theory (p. 6163)

I pursued triangulation as a way to ensure credibility and trustworthiness, collecting data from multiple points, including: interviews with Resident Participants and Focus Groups, with participating Certified Nurse Assistants (CNAs) and Social Workers; and Observational Data, gathered through observation of the setting and examination of documents and artifacts. Miles and Huberman (1984) describes triangulation as the

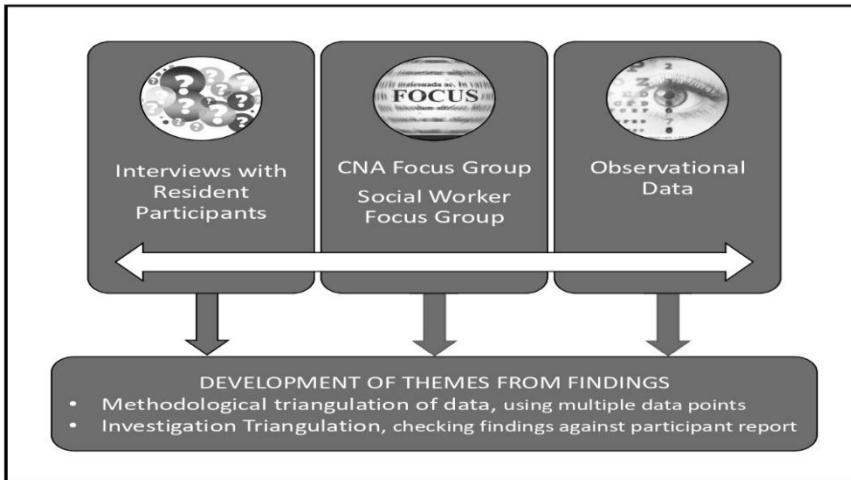
process of using multiple points of data, from multiple sources, and viewing them from multiple angles to increase the reliability and validity of the findings. Figure 3.1 depicts these the multiple types of data sources used in this study and how findings were compared between these multiple sources.

Analysis from three or more unique data sources produces rigor in qualitative case studies (Lather, 2007; Yin, 2018). In addition to these multiple sources of data, I created an audit trail and produced field notes and analytic memos throughout the course of this study. These provided a valuable tool for examining the findings, including exploration of my positionality as a researcher with an extensive background working in LTC. Further, the incorporation of member-checking or face validity (Lather, 1987; Lather, 2007), allowed an on-going process evaluation regarding the analysis of the data, honoring what Guba and Lincoln (1981) described as “the backbone of satisfying the truth-value criterion” (p. 110). I incorporated member-checking at the beginning of each Resident Participant interview and throughout the process of analysis, including at the conclusion of my analysis, sharing patterns and themes and asking Resident Participants and members of the Focus Groups to confirm accuracy and make suggestions for further analysis.

Although my study, like all case studies, is not intended to explore a representative sample and does not serve to provide statistical generalization to a larger population (Gomm, Hammersley, & Foster, 2000; Yin, 2018), a methodologically rigorous study, bounded by environment, can provide important findings that can help develop theory from the relationship of theoretical proposition and analysis (Small, 2009; Yin, 2018). As including reflexive work on one’s positionality as a researcher promotes

both transparency and trustworthiness, the following section represents some of my professional commitments to this study.

Figure 3.1. Types of data sources.



My Positionality

Glesne (2016) and Lather (1987) described the importance of the reflexive stance, which allows the researcher to honestly evaluate the *where* of themselves, to think more critically about the research and the data that emerges. My experiences over my life course inform my work and are important to address.

Past

I began thinking about the way younger residents experienced their world a few years ago. I had resumed working in LTC, following my return to the United States. Although I had worked in various settings that provided care for seniors, I left that life when my husband and I moved overseas. When we returned after nearly three years, I

resumed my studies and following completion of my master's degree program, returned to LTC. I was hired as a Licensed Master Social Worker (LMSW) for one of the largest LTC centers on the Eastern seaboard, where almost 300 residents lived, and 300 others worked. I noticed significant changes, especially in the nursing home population, which now had many younger residents, below the age of 65. Where were all these younger persons coming from??? Why were they living in LTC???

I was assigned two different units and of *my* 88 residents, more than 20 were younger. Many of these persons had experienced traumatic injuries, related to drug use and/or risky behaviors. Most were estranged from family and had limited, if any, social networks. The majority experienced comorbidity with mental illness and displayed behaviors such as physical or verbal aggression, defiance, and yelling.

All younger residents I encountered were poor and dependent on Medicaid, which funded the cost of their care. After a few months, I was promoted to the position of Psychiatric Liaison, and became responsible for scheduling visits between residents and the contracted psychiatrist. As a result, I became acquainted with the additional five units of the home and found most persons diagnosed with severe and persistent mental illness were younger. These younger residents were sometimes involved in altercations, usually with staff, who frequently described them as distracting, defiant, disruptive, and dangerous. Younger residents often received heavy medication on an as-needed basis. They were, generally, labeled as burdensome and their behaviors often led to ever-increasing medication and social isolation. The facility policies, targeted for older persons, failed to address the complex needs of these younger residents who, due to severity of need, had the potential to remain in LTC for decades, during years defined as

the *prime of life* (Lachman, Teshale, & Agrigoroaei, 2015).

Present

I am interested in how perceptions influence decisions among health care providers. More specifically, I am interested in how perceptions influence the delivery of services for younger persons living in LTC. I have many years of experience in LTC and I am passionate about finding ways for younger residents to live the best of their lives for the whole of their lives. This passion informs the way I approach my research, including the way I want to share what I learn about the lives of non-traditionally aged residents with those who develop and review the policies, procedures, and documents that drive the delivery of services in institutionalized settings.

Future

I believe that repeated interviews with informants will build upon existing relationships and create additional trust between myself and study participants, allowing an opportunity to move beyond a process of detached assessment and toward a research partnership involving a process of looking and listening, of participating and asking, seeking to understand more about how the growing population of non-traditionally aged residents experience their social world, within the context of the LTC setting.

I aim to establish a similar trust between myself and facility workers, including administrative staff, certified nurse assistants (CNAs), and Social Workers. Although I anticipate my status as a former employee of this facility will help establish trust between myself and various facility insiders, I am mindful of the importance of ongoing transparency and trustworthiness.

Additionally, I remain aware that this passion creates bias. I try to be careful not to

romanticize my research or I may miss critical information that arises from the study.

Some things I see as especially important for me to address:

- I have experience as a Social Worker in the LTC setting. I also have experience as an LTC administrator. These positions are often in opposition, regarding what might be *best* for the resident or what might be *best* for the facility. As a Social Worker, I must always be aware of my tendency towards cape-wearing advocacy, which serves nothing well except the creation of barriers between and within organizations. Plans of care are created through multiple disciplinary interactions and, as a researcher, I must remember to respect the dignity and worth of all stakeholders.
- I *was* an LTC Social Worker. I no longer am one. I have privilege as a white woman who has the means to return to school, without financial burden. Collins (1986) explained how the multiple roles of one's identity create barriers and opportunities between a researcher and participants. I have, in many ways, escaped LTC and must remain mindful of my insider/outsider stance. This affects my approach to this study. Field notes and analytic memos help me triangulate what I learn, what I see, what I know, and what I feel.
- I am middle aged, and within the age range of these non-traditionally aged LTC residents. I have experienced significant health concerns over my lifetime and must remain ever-aware of how my personal concerns and fears may influence my research and analysis.

Brayboy and Deyle (2000) discussed tensions researchers confront when crossing the border between insider and outsider. Researchers who identify with the studied group “have an obligation to strike a balance between participating and observing” (p. 165). Incorporating a reflexive stance allows me to remain aware of how my own attitudes, perceptions, and expectations influence the way I operate in, and respond to, my situatedness within the LTC setting and straddle the line between insider and outsider.

Ontological and Epistemological Standpoint

Grix (2002) explained ontology as “what’s out there to know?” (p. 180). Ontologically, I consider myself to be an Interpretivist and “what’s out there,” is relative. I believe reality is observable, but one’s experience(s) and belief(s) influence the meaning of that reality. I seek to examine truth as dynamic reality-in-context, created and interpreted through mutual agreements and relationships between people, bounded by the social environment. The way one makes meaning from lived experiences, within a particular social environment, is explained in my study through Cooley’s (1902) Theory of the Looking Glass Self, which explains how perceptions and meaning-making are influenced by one’s perceptions of the perceptions of others. What and who we are may be explained not by what we believe ourselves to be... not what others believe us to be... but, rather, what we believe others believe us to be.

When I consider how I view the nature of the *world* I wish to investigate, I am drawn to the way reality is constructed. I believe what is real is a created understanding, with interpretations influenced by time, space, and place. What is true becomes true because individuals who operate within a particular social structure determine it *as* true.

This interpretivist approach offers opportunities for a richer understanding about non-traditionally aged residents, as explained by Oedenhoven (2017), who described the emic approach to research as one of engagement, leading to deeper understandings of a particular culture. My approach is not that of a disengaged observer. My perspective regarding LTC certainly affects my interpretations and I am challenged to balance my own insider/outsider perspective, which “reflects a special standpoint on self, family, and society” (Collins, 1986, p. S14).

Though truth is dynamic and shifts as attitudes, values, and mores shift, what is true is what is believed to be true. Truth is reified over time and is maintained through institutional and generationalized beliefs, which insulate and elevate *some* members of society, and separate and subjugate *others*; however, the relationships experienced (or not) by persons within a social environment create and maintain opportunities for both marginalization and connection. This post-critical viewpoint moves beyond Critical Theory’s determinant stance *that* disparities are, and seeks to discover *why* disparities are (Noblit, 2004). Post-critical thought considers the experiences of disparities found within groups, in addition to the experiences between groups. Such consideration may be relevant for my population who, although sharing commonalities with other LTC residents regardless of age, have experienced individualized, and often multiple, traumas leading to admission within an LTC environment. Post-critical thought emphasizes the relational experience(s) and the dynamic power of relationship for change, as described by Noblit (2004).

This stance also reflects my role as a Social Worker. Social Work practice looks at human behavior in the social environment, and focuses on behavior and, more

importantly, the interpretation and meaning of behavior as a product of the social environment where individuals function and exist. Although there are different schools of thought in Social Work, the position which *speaks* to me is the value of relationship, as outlined by the classic work of Helen Harris Perlman (1979), who described relationship as the most important tool available for understanding the world of human beings and the meaning human beings find in their world.

Research Setting

This study was conducted at a large non-profit LTC facility in the southeastern part of the United States, which I will call Golden Acres. At the time of this study, almost 300 persons lived at Golden Acres and over 300 worked there. The original structure was built in the 1970s, expanding over the years, to include six skilled nursing units, one in-patient rehabilitative unit, a fully-equipped physical therapy building that served both in-patient and out-patient clients, and a small conference center, all of which sprawl over a 10-acre campus. The facility is associated with a large local hospital, which “feeds” admissions on a continual basis. The advent of Assisted Living and other living options has not affected the rate of admissions. “Beds” do not stay empty long.

The Administration offers what the Director of Nurses calls “an attractive benefits package” for employees, which includes healthcare, retirement savings, and a unique program of support for CNAs who wish to enroll in nursing school. These benefits are far more generous than other area nursing homes and the Administrator states that these benefits contribute to lower staff turnover and better worker satisfaction. Indeed, at the time of this study, most employees had worked at this facility over 10 years, and many reported working at the home for over 20 years.

I was familiar with this site, as I worked there three years before, as an LMSW and Psychiatric Liaison. I left my job to enter the doctoral program at the University of South Carolina and I recall many of the current staff listening to countless drafts of my letter of interest to the graduate program. I am familiar with many of the Administrative, direct care, and Social Work staff. Additionally, I had the great fortune to conduct a pilot study for my dissertation at Golden Acres, in the summer of 2018. This pilot study was discussed in more detail in Chapter 2.

Appropriateness of the Setting

Study settings should be chosen carefully to correspond to research questions and provide access to an environment where questions can best be answered (Lofland, Snow, Anderson, & Lofland, 2006). The selection of Golden Acres as a research setting provided me access to different groups of participants, which allowed me to pursue multiple points of data, including interviews, Focus Groups, and facility documents. I have access to this setting and have established what I perceive to be a measure of trustworthiness between myself and the Administrative staff.

These relationships were especially important in the beginning phase of this study, as I relied on Administrative staff and Medical Records personnel to provide access to resident records that were several years old. This staff also provided me with access to encrypted data, through Electronic Medical Records (EMRs). Administrative staff (Administrative Assistants, Medical Records personnel, and Unit Secretaries) also scheduled conference and treatment rooms that I used to review records and interview the four Resident Participants.

I chose this setting because of the number of non-traditionally aged residents and

because of existing professional relationships. At the beginning of my study, the patient manifest noted 48 permanent residents under the age of 64, which echoed the proportion of younger persons living in LTC settings in the United States. Most of the younger residents met my study criteria and I believed I could select a sample of Resident Participants that could compellingly illustrate the residential experience of non-traditionally aged residents.

My relationships with formal and informal leaders of Administrative, Care, and Support staff provided both access and freedom. The facility Administrator, Director of Nursing, and the Director of Social Services supported my work and allowed me free access to the facility. I received great help from the floor nurses and aides, who always made sure the Resident Participants were dressed and ready for my visits. To me, this indicated high levels of the acceptance of my work and ultimately yielded multiple points of data from which I was able to triangulate findings for this study. Additionally, this access allowed me to fade into the background and become what one of the CNAs called “a part of the furniture.” This proved important while I conducted observations, allowing a less curated viewpoint of this LTC setting.

Units of Analysis Within the Setting

My study is an embedded case, bounded by this particular LTC setting. Figure 3.2 illustrates that the case is bounded by the LTC setting of Golden Acres Extended Care (Golden Acres), which is represented by the outside line. The experiences, perceptions, and perceptions of experiences of the resident participants and focus group members are bounded by the social environment in which persons live and work... in this case, Golden Acres.

Within this setting lies the individuals and groups of my study, namely the four Resident Participants, the CNA Focus Group, and the Social Worker Focus Group. Although these individuals and groups are located within the LTC setting, they are unique. Additionally, they are separated, with resident participants on one side of the figure and focus groups on the other.

In the LTC setting, residents and staff are defined as either persons who receive care, or persons who receive it. Regardless of this division, the resident participants and staff members interact and frequently develop social connections. The dotted line between the two groups represents the flow of relationship that exists between residents and staff in the LTC setting and illustrates how findings of this study are compared between and within groups.

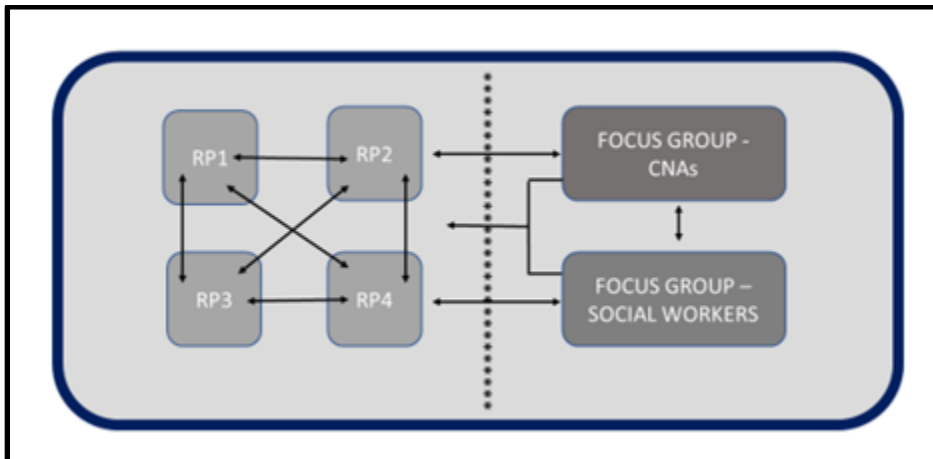


Figure 3.2. Embedded units within Golden Acres

Engagement with the Facility

Following IRB approval for this study, I contacted the Administrative staff of Golden Acres to outline the purpose and protocol for this study. All levels of staff I encountered at Golden Acres were supportive of this work and seemed curious to learn about my research. I was transparent about my study and worked hard to assure workers

that I was not “out to get them” or “wanting to embarrass the nursing home.” My openness allowed me to establish a positive relationship with people who granted me entrée into this world, and I believe that *they* believed I was trustworthy.

Chauduri (2017) described work within quasi-private settings, such as nursing homes, as difficult for researchers, where access is superficially granted to all visitors, but restricted by gatekeepers. I experienced very few barriers to my study despite the rigid hierarchies present in healthcare settings and my former status as an employee seemed to provide a certain level of credibility, though there were exceptions. One Social Worker was initially suspicious of my intentions and needed repeated assurances that my study was not intended to evaluate her work. This same Social Worker expressed hesitancy to participate in the Focus Group, though she agreed to take part after reassurances that the Focus Group would not be recorded.

My past work and research at Golden Acres established me as someone who was seeking a truthful story, not a sensational one. I did not take this good will for granted, and I know it made the initial tasks of my dissertation less difficult to navigate. My investment in relationships with Administrators and direct care workers provided dividends and allowed me to move forward with far more ease than I anticipated.

Engagement with the Residents

As I designed this study, I reflected on how my previous work in this setting might help me engage with potential Resident Participants. I was a known face and had worked across the multiple units of Golden Acres and was recognized as a quasi-member of the community – not quite *of* it, but not apart from it, either. Over the course of this study, I was repeatedly reminded of this status as residents and family members would

greet me, asking: “How’s school going?” and “When are you coming back?” When I shared plans for my dissertation, some residents asked me to explain what that meant; however, more than once, residents shared encouraging words. One of the older female residents, who I knew as Miss Elizabeth, was retired from USC. She told me: “That is quite an accomplishment. Take time to enjoy the process. I am very proud of you!” Later, as I began the process of selecting participants, one of the younger male residents with whom I previously worked, Melvin, said: “I remember when you told us you were going back to school. Look at you now! You are almost done, kid!”

My status as an insider provided an enhanced level of access I would not have enjoyed if I had been a stranger to this community. My history and lived experience helped me know ways to approach residents, how to assess mental health histories, what documents to request, who to enlist as brokers between me and younger residents, how to read schedules to avoid conflicts with activities and scheduled care, and what door was accessible during weekend hours.

The benefits of my insider status allowed me to collect a better, and more complete, set of data about, and from, Resident Participants and supported my efforts to answer the identified research questions.

Engagement with the Staff

My history with Golden Acres also benefitted my attempts at engaging staff. Golden Acres appears to have less staff turnover than most institutions of care. Staff retention is an important aspect of quality of care and resident well-being; however, annual staff retention reports of nursing home employees noted that nationwide turnover rates of LTC workers exceeds 50%, with estimates of turnover as high as 63% industry-

wide (American Healthcare Association, 2019). Despite the passing of over three years, I noticed that almost all of the support staff and most of the direct care staff had remained in place. These familiar faces provided support for my research and *talked it up* with others. On more than one occasion, staff members pulled me into conversations and shared my study design with others. Lawrence, who supervised several Support staff members, stopped me as I walked down the hall one day. He put his arm on my shoulder as we walked into the Laundry room, announcing: “Hey, y’all, look who’s back! Sara is doing some research for her degree. Be sure to help her if you can.”

I have no doubt that my status with staff contributed to the level and accuracy of data I was able to collect during this study. I was known among most of the formal and informal staff leaders and this allowed me to access staff areas, such as nursing stations and breakrooms, during my field observations. Care staff also made efforts to schedule assistance with ADLs, so care did not conflict with the interviews. One of the CNAs, Cynthia, who worked with one of the Resident Participants in this study promised: “I am going to make sure that Walter is ready when you come. Don’t worry. I got you!”

Summary Chart of Methodology

Figure 3.3 depicts a visual representation of the methodology used for this research, illustrating the methodological steps taken during before, during, and after data collection.

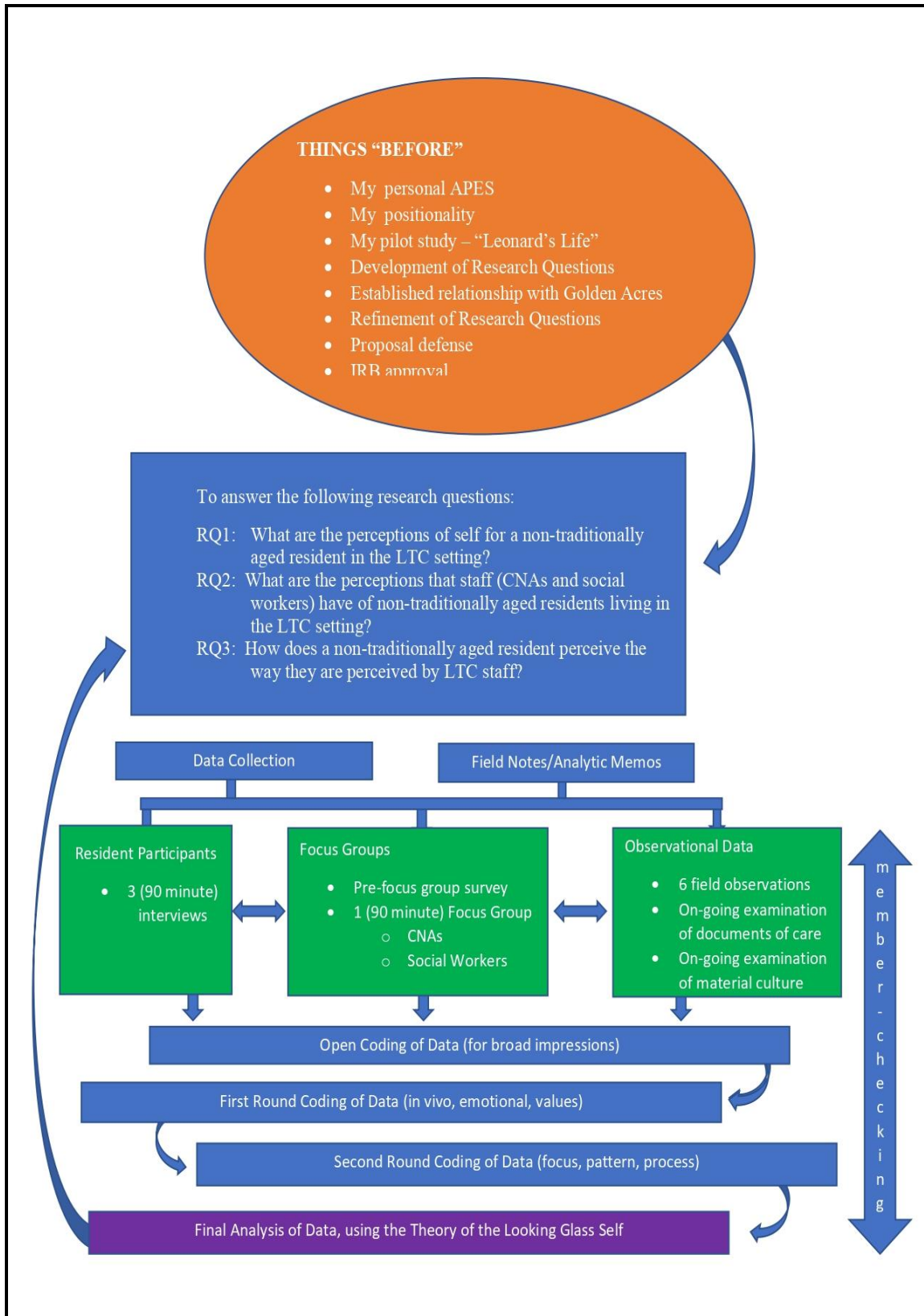


Figure 3.3. Visual representation of research methodology

Sources of Data and Sampling

Triangulation, through the use of multiple sources of data, can assure content validity in case study research (Yin, 2018). This case study considers evidence from multiple sources of data, as previously discussed. The use of multiple sources allows for the examination of perspectives across and between groups, helping provide a deeper understanding of the residential experience of non-traditionally aged residents.

I chose data sources to correspond with The Theory of the Looking Glass Self (Cooley, 1902), which notes that what is true is a reflection of multiple perceptions of the self, of others, and of the perception of others' perceptions. These multiple sources allow me to more fully describe the residential experience of non-traditionally aged residents of the LTC setting and answer the research questions outlined throughout this study.

Direct Observations

Six weekly observations were conducted over the length of this study, with each observation lasting approximately three hours, scheduled to capture different shifts and workdays. Three observations were conducted outside of common work hours, with two of these observations taking place during the third shift (11:00 p.m. – 7:00 a.m.). Three observations were made during common work hours (9:00 a.m. – 5:00 p.m.). These observations were scheduled to incorporate data from all shifts, including the observation of mealtimes at both the first and second shift, as well as the shift cross-over period, between 2:30 p.m. and 3:30 p.m.

Observations were conducted in common areas throughout the LTC setting like activity centers and dining rooms. Some observations took place at the nurses' stations, which provided clear views of common areas, dining rooms, resident rooms, elevators,

and nursing carts. The nurses' stations were also a common gathering place, particularly during shift changes and evenings, after most residents had been helped to bed.

Observations were also conducted at the various entrances of the facility and the catwalk/breezeway, which connects the Administrative offices, the rehabilitative unit, and the skilled care units, where permanently placed residents live. I used these observations to compare findings from Resident Participants and Focus Groups. Simply put: I used observations to analyze what participants said with what participants did.

Examination of Facility Documents

Documents (admission data, assessments, Brief Interview for Mental Status [BIMS] scores. Preadmission Screening and Resident Reviews [PASRR] and resident face sheets were examined to evaluate whether participants met study criteria and to check against resident and worker report. Information from these documents contributed to the fidelity of this study and adherence to study criteria, confirming the age, income level, mental health diagnoses, cognitive status, familial ties, and assignment of responsibility of the Resident Participants involved in the study. As state regulations required resident status to be updated and assessed after every significant change or 90 days, data were always current. Prior to every interview, I verified the cognitive status of Resident Participant(s) with the respective Social Worker, assuring the resident had experienced no significant change to cognitive status that impaired the ability to fully participate in the study.

Facility documents, including scheduling records and records of hiring dates were used to determine the adherence to study criteria for Social Workers and CNAs. I reviewed these documents prior to Focus Group meetings, with the Nurse Managers

providing shift schedules and verifying length of employment of CNAs. The Director of Social Services verified employment dates and certification of Social Workers, prior to the Social Worker Focus Group.

Interviews/Focus Groups

Most data for this study came from the non-traditionally aged Resident Participant interviews and Focus Groups with CNAs and facility Social Workers. I analyzed these data to answer research questions about the residential experience of non-traditionally aged residents.

Sampling/Selection. To best answer the research questions, purposive sampling was conducted for each of the three groups. Three purposive samples were created to allow me to examine perspectives of non-traditionally aged residents, CNAs, and facility Social Workers. I chose this non-probability sampling method based upon my knowledge about the subject being researched (Charmaz, 2014). I chose this method to match common characteristics of non-traditionally aged residents, as outlined by the Centers for Medicare and Medicaid (2016) and Harris-Kojetin and colleagues (2013). Yin (2018) described this method as purposeful selection, and in this study, the terms *sampling* and *selection* are used interchangeably. Purposiveness allowed for the best collection of data about non-traditionally aged persons living in the LTC setting, capturing the perceptions and words of persons living and working within this bounded environment. In this section I discuss the sampling strategy and recruitment process for the three groups involved in this study: Resident Participants, CNA Focus Group, and Social Worker Focus Group.

Resident participants. This study relied primarily on perspectives of Resident Participants, with recruitment of residents a key to the success of this study.

Understanding the residential experience of non-traditionally aged persons living in the LTC environment cannot be understood without engaging non-traditionally aged residents and asking them to share their perspectives and experiences, through their own words. I conducted six intensive interviews to explore the first research question: RQ1: *How does a non-traditionally aged resident perceive himself or herself, as a resident of the LTC setting?* For this study, a Resident Participant was defined as a permanently admitted resident of the LTC setting, younger than the age of 65, who met the study criteria, and agreed to participate in the study.

Although Golden Acres employed a Director of Social Services to oversee the Social Work program, I did not rely on this supervisor to identify possible Resident Participants; rather, I worked with Social Workers assigned to the units to identify possible participants. These facility Social Workers were responsible for the assessment of the persons living on the units and, generally, possessed a more intimate understanding of the residents than Administrators, who were removed from the day to day events of the residents. I had a goal of 4-6 participants for this study, including four Resident Participants and two alternate Resident Participants, who would be invited to the study, should a person in the original group choose not to participate, withdraw from the study, or if saturation was not reached.

The Social Workers identified younger residents from the facility manifest. Although this manifest was published daily, the census manifest, as of the date of the IRB approval for this study, was used to identify a list of residents younger than 65 years of age and served as a sampling frame for non-traditionally aged residents living at Golden Acres. The date of IRB approval was used as a baseline for all resident data,

including BIMS scores, census data, and face sheet information.

After the initial process of creating the sampling frame, Social Workers were asked to identify residents who reflected common characteristics of non-traditionally aged residents, as outlined by the Centers for Medicare and Medicaid Services (2016) and the Office of Inspector General, Department of Health and Human Services (2007) PASRR report, including being permanently disabled, experiencing low SES, experiencing estrangement from family, and living with a diagnosis of (at least) one mental illness. This study also required Resident Participants to have the cognitive ability to fully participate in the interviews. Only Resident Participants assessed as cognitively sound, as determined by staff assessment using the BIMS test within the prior three months, were considered for this study, with those residents scoring less than 12/15, excluded.

Further, all potential Resident Participants were required to serve as their own responsible party and fully and independently consent to the study, as indicated through face sheet or other documentation. Persons not meeting these criteria, or who experienced a change in cognitive status, were excluded from this study. Table 1 summarizes the study criteria for Resident Participants.

Once all potential participants were identified, names were placed in a basket and drawn, until four potential Resident Participants, and two alternate Resident Participants, were selected. Following this selection, study criteria was again confirmed through a review of facility documents. After I had determined that selected potential Resident Participants met the outlined study criteria, I scheduled a time for the respective Social Workers to introduce me to potential Resident Participants.

Table 3.1. *Study Criteria for Resident Participants*

<u>Study Criteria for Resident Participants</u>	
<u>Criteria</u>	<u>Assurance of Criteria</u>
Low SES	Face Sheet
Permanent Disability	Medical Record
Mental Illness	Medical Record
Family Estrangement	Social Assessment
Cognitively Sound	BIMS
Own Responsible Party	Face Sheet

Recruitment strategy – Resident Participants. Following identification, potential Resident Participants were recruited, through personal introduction, from the Social Worker, who accompanied me to each resident’s room, where I introduced myself, the study, and the role of Resident Participants for this research.

This initial meeting allowed me to clarify the purpose of the study and answer any broad questions regarding the research. The facility Social Workers provided an important social bridge between these residents and myself, allowing me to build a level of trust between myself and those from whom I hoped to learn. Recruitment continued in this manner until a total of six Resident Participants (four participants and two alternates) had been identified. All potential Resident Participants I approached agreed to participate and appeared eager to contribute to the study. For example, Edgar, one of the Resident Participants, expressed: “Are you kidding? I have been waiting to do something like this!” and Mike, another Resident Participant, told me that participation would give him something “to look forward to.” Initial interview times were scheduled with all identified Resident Participants during this first meeting, following their agreement of participation. Appendix D outlines the timetable used for this research.

Focus Groups. I conducted two Focus Groups to explore the second research question: RQ2: *How do workers in LTC perceive non-traditionally aged residents living in the LTC setting?* One Focus Group was held with CNAs who have frequent personal contact with the residents. A second Focus Group was held with facility Social Workers, who have a primary role in initial and follow-up psycho-social assessments of nursing home residents. Both Focus Groups involved a purposive sampling strategy and persons not meeting the study criteria were excluded from participation in the Focus Groups.

Although I planned for only one Focus Group for both CNAs and Social Workers, I did not limit my study to this initial planning and allowed extra time to conduct additional Focus Groups, should the initial group not provide information that was valuable and relevant to the study. This proved unnecessary, as one Focus Group from each designated group proved adequate to answer the research question. Findings from these Focus Groups are discussed in the subsequent chapter.

Recruitment strategy – CNA Focus Group. The aim of the CNA Focus Group was to examine perceptions of direct care workers regarding younger residents in the LTC setting and I was interested in exploring the thoughts of CNAs regarding non-traditional residents. Table 3.2 summarizes the study criteria for CNAs participating in the Focus Group.

I worked with Nurse Managers to identify a list of CNAs meeting the study criteria and leveraged relationships with floor nurses to help recruit potential CNA Focus Group members. The list served as a sampling frame for the CNA Focus Group.

Table 3.2. *Study Criteria for CNA Focus Group*

<u>Study Criteria for CNA Focus Group</u>	
<u>Criteria</u>	<u>Assurance of Criteria</u>
Certified Nursing Assistant	Nurse Manager
Scheduled Full Time	Nurse Manager
Employment by facility	Business Office

In keeping with established Focus Group methodologies, I limited the number of Focus Group participants to less than 12 (Berg, 1989; Krueger & Casey, 2000). My previous experience at Golden Acres created some angst for me with that size of a group, as I was aware that larger groups might become unwieldy; therefore, I set my goal for this Focus Group at less than nine CNAs., which I believed would allow for a broad, but controlled, discussion about non-traditionally aged residents (Berg, 1989).

Initially, I recruited for the CNA Focus Group by posting a flyer advertising the Focus Group at nurses' stations of the units where Resident Participants resided, in staff lounge areas, and on the carts on wheels, commonly referred to as *COWs*, where CNAs entered information into the EMR for each resident to which they had been assigned. Appendix E depicts this recruitment flyer.

Although most CNAs employed by Golden Acres met the criteria for participation, relatively few expressed an interest regarding participation in the study. I noticed the flyers disappeared after a few days and those that did remain were often obstructed by additional flyers, featuring notices about changes to policy, compulsory trainings, and reminders of work expectations.

After three weeks (and very little response, with only two CNAs responding to recruitment efforts), I changed my recruitment strategy and began talking more freely,

hanging out at the nurses' stations at shift changes and talking with some of the nurses and CNAs with whom I had previously worked. I shared details about the Focus Group and my hope to have CNAs participate. I mentioned that I valued their perspectives and thought CNAs could contribute important information to the study. Some long-term CNAs began to approach me and ask for more details of the study, promising to recruit potential participants. This sampling strategy proved a little more successful and illustrated the importance of relationships in closed or semi-closed environments. I am not sure if recruitment for the CNA Focus Group would have been successful without the support of long-term employees with whom I had built trust. In the end, six CNAs were recruited for this Focus Group.

Recruitment strategy – Social Worker Focus Group. The aim of the Social Worker Focus Group was to examine Social Workers' perceptions of younger residents in the LTC setting. I was interested in exploring the perspectives of Social Workers, who offer a unique perspective in the LTC setting, as they are actively involved in initial and on-going assessments of residents, which inform the multiple-disciplinary plans that drive the delivery of services for residents. To gather perspectives of Social Workers about the residential experience of non-traditionally aged residents living in the LTC setting, I conducted a Focus Group with non-administrative Social Workers.

I worked with the Director of Social Services to assure that all non-administrative Social Workers met the study criteria. The Director of Social Services was very supportive of the study and provided a census sampling frame of seven, non-administrative Social Workers that met the purposive criteria for participation. Additionally, the Director of Social Services sent out an email to all Social Workers

about my study, prior to recruitment. I personally approached the Social Workers and presented information about my study. Despite some initial hesitation by one of the Social Workers, each agreed to participate in the study. Table 3.3 summarizes the study criteria for participants of the Social Worker Focus Group.

Table 3.3. *Study criteria for Social Work Focus Group.*

<u>Study Criteria for Social Work Focus Group</u>	
Criteria	Assurance of Criteria
Licensed Social Worker in the state of study site	State Licensing Board
Employed in non-administrative position	Director of Social Services
Scheduled Full Time	Director of Social Services
Post-probationary employment	Director of Social Services

Data Collection

In this section, I describe the methods I used to examine data gathered from multiple sources, including Resident Participant interviews, Focus Groups, and Observational Data.

Resident Participant Interviews

Beginning in April 2019, I conducted three in-depth one-on-one interviews with each Resident Participant to answer the research question: RQ 1: *How does a non-traditionally aged resident perceive himself or herself, as a resident of the LTC setting?* Interviews were spaced two weeks apart. and were conducted in the Resident Participant's room or in another private area, such as a conference room or treatment room. Privacy was an issue during these interviews. Even when we were provided areas that were, ostensibly, private, the interviews were often interrupted by staff who were looking in on the resident, needed to access material in the treatment room, used the room

to pass through one wing to another, or simply wanted to “say hi.” These interruptions occurred regardless of notes I taped on the outside of locked doors that read: “Interview in Progress. Please, Do Not Disturb.” These notes were often over-looked and locked doors were opened with pass-keys. It should be noted that though I found these interruptions highly distracting, the residents seemed unaffected by them, either greeting the staff member or continuing to speak as though nobody else was with us. None of the residents mentioned the interruptions after the staff members had left the room, even if the interview was repeatedly interrupted by others. Upon experiencing these interruptions, I became hyperaware of the rate of interruptions that occurred during formal and informal encounters with study participants.

This was magnified when I listened to recordings of the interviews with Resident Participants and heard knocks, keys, doors opening, the sound of rubber-soled shoes walking on linoleum, shuffling of papers, more walking, apologies, and doors closing. The recordings highlighted how these interruptions bothered me, but not the Resident Participants. Whenever they occurred, I apologized. The Resident Participants dismissed the interruptions, often with a shrug or the wave of a hand and continued the interview. When asked about an interruption, Leonard shrugged, saying “It’s no big deal.” Edgar and Mike were *non-plussed*, as well, and responded to my apologies about the interruptions with: “Whatever.” Walter engaged in conversation with staff who interrupted, saying hello, introducing me, and sharing information about the study.

Each of the three interviews with the four Resident Participants was digitally recorded to assure accuracy of data reporting and scheduled to last 60-90 minutes. I was initially concerned about the length of the interviews and whether the Resident

Participants could remain focused for that length of time and if it would present physical difficulty for the participants, but no Resident Participant expressed discomfort or distress about the interviews. Walter frequently commented: “I could talk all day!” and all Resident Participants asked to confirm the next interview before I left. “Can you circle it on the calendar? I don’t want to miss it.” said Mike.

Resident Participants received \$25.00, per interview, as an incentive for participation, with this incentive deposited into their personal fund account, following the last interview. No Resident Participant dropped from the study and all were able to participate for the length of the research. Although the interviews were semi-guided, a protocol framed each interview (Appendix F depicts the protocol guidelines for Resident Participant interviews.) To create alignment in data collection and to allow for comparison of data between and across the group of Resident Participants, the same interview protocol was used with each participant during each interview, with each interview having an overall theme.

Interview One. The first interview was held, primarily, as a “get to know you” session, during which the study was explained, and informed consent obtained. This session was intended to gain trust and gather descriptive information and ask questions about the self-perception of Resident Participants. To help establish rapport and provide some context for future interviews for the participants, I conducted a brief, open interview, which was far less structured than subsequent interviews. Field notes were made immediately following interviews, usually in the parking lot of the LTC facility, as I wanted to capture my thoughts as quickly as possible, following the interviews. I also captured my impressions of Resident Participants through a series of analytic memos.

Transcripts were made in the interim between first and second interviews and second and third interviews in order to guide subsequent interview questions. Open coding was conducted with each transcript to allow for initial interpretation of the raw data. The process of open coding, as described by Glaser and Strauss (1999/2017), was used to categorize raw data into broad ideas and concepts. I completed open coding iteratively between first and second interviews and second and third interviews as well as after the third interview for each participant.

I wrote analytic memos after each interview and tried to listen to the recordings within one or two days, writing down my impressions through open-coding during these first listens. This open coding was conducted before I created the transcripts of the interviews, as I did not want to be interrupted by the process of writing during the first listens. The transcriptions of interviews, field notes, and analytic memos were uploaded into the MAXQDA 18.0.0 (2018) software system, in preparation for additional coding and analysis.

Interview Two. Prior to the second interviews, I emailed the respective Social Workers to assure that the Resident Participant had no change of condition and continued to meet the study criteria. The second interview was conducted two weeks after the initial interview and consisted of a semi-structured interview that followed the protocol of open-ended questions regarding the perception of resident experience, including social relationships and how the Resident Participant believed they were perceived by others. I opened the second interviews by reminding the Resident Participant that this was the second of three interviews and asked if they had any questions, then I clarified any questions I may have had regarding data from the first interview. Next, I began to ask

questions refined from the initial interview to check findings and further explore the data. This approach was similar to interviews conducted during my pilot study, using questioning conversations to gather information while connecting with the Resident Participants. This technique responded to my strong desire to partner with the Resident Participants. I very much wanted them to not feel studied in a distant sort of way. Instead, I took great care to thank the Resident Participants over the course of this research.

In summary, the second interview began with a thank you, followed by a member-checking session, where I asked the Resident Participant to check my understanding of the prior interview. I also asked them if they had any questions, prior to initiating the protocol for this second interview.

As before, I made field notes immediately following these interviews, conducted open coding of first listens, and transcribed the interviews, uploading transcripts, memos, and fieldnotes to MAXQDA.

Interview Three. A third interview was conducted two weeks after the second interview and consisted of a semi-structured follow-up interview, to clarify any questions regarding collected data from prior interview sessions. Once again, the resident was thanked and given the opportunity to ask questions, prior to this semi-structured interview. This final interview also included a wrap up period, where I, once again, thanked the Resident Participants, and asked them if they had any further questions. All Resident Participants had a common request - a copy of the finalized dissertation. As one Resident Participant, Walter, told me: “Everyone likes to see the result of things they contributed to.”

I put great thought into the termination of my research relationship with this

group. During the interviews, the Resident Participants in this study sometimes expressed feeling what Edgar called “different,” what Leonard called “apart,” and what Mike described as “unheard”. I did not want to contribute to these feelings. I was transparent about my role as a researcher and the study, including the number of interviews I would conduct. At the last interview, I took the time to allow the Resident Participants to ask me questions and worked to tie the process of the interviews together. To wrap up my researcher role with the Resident Participants, I mailed a personal thank you note, with my business card, assuring them that I would deliver a copy of the dissertation when they were printed. Field notes were made immediately following this last interview. Following the final interviews, incentive payments were deposited into each Resident Participant’s personal facility account and receipts were provided to the resident’s respective Social Worker.

CNA Focus Group

I conducted one Focus Group with six CNAs to help answer the second research question: RQ2: *What are the perceptions that staff (CNAs and Social Workers) have of non-traditionally aged residents living in the LTC setting?*

It was extremely difficult to schedule this Focus Group, due to the multiple schedules and personal obligations of the CNAs. After much communication, a time and place was selected to accommodate CNA requests regarding scheduling and privacy, with the Focus Group conducted in a location outside the LTC campus, in the banquet room of a local restaurant. The Focus Group was composed of six CNAs, who were scheduled to work various shifts. Prior to the Focus Group meeting, participants were sent a pre-Focus Group survey that collected demographic data and answers to general questions about

working with younger residents in LTC settings. This Pre-Focus Group Survey - CNAs is included in Appendix G.

Participants were instructed to return this survey, via email, two days prior to the meeting, as answers to survey questions helped to inform the protocol used for the CNA Focus Group (Appendix H). The CNA Focus Group lasted 90 minutes and was not digitally recorded, as the CNAs had specifically requested the interview not be recorded, for fear of retribution if they said something that might be misinterpreted by Administrative staff; however detailed notes were taken by a research assistant, which allowed me to focus on the questions and answers. This assistant was briefed on the study and researcher needs, prior to the Focus Group. I built in time to allow for flexibility in the Focus Group, as I anticipated the answers to the protocol questions could be completed in about 1.5 hours. I anticipated this Focus Group to last approximately 90 minutes, but informed the participants to block about two hours to allow for extra time, if needed. The protocol questions were used to guide responses to best answer the research question; however, I also wanted to allow for free expression about perceptions of younger residents

My aim during the Focus Group was not to ask Focus Group participants about how they perceived particular residents; rather, I wanted to gather information about how CNAs generally perceived younger residents. I served as the facilitator of the Focus Group and began by providing informed consent, discussing issues of privacy regarding information that was shared in the group.

The purpose of this Focus Group was to gather information about how CNAs generally perceive younger residents and whether those perceptions are echoed in

observations I made while *on the floor*. For example: if younger residents are perceived as disruptive or demanding, are they avoided by staff? Is the delivery of care influenced by the way younger residents are treated by direct care staff? An analytic memo was made immediately following this Focus Group and findings were compared to data from other data sources, including observations, examination of documents, and Resident Participant interviews. Notes from the Focus Group were open coded at the first reading and later entered into the MAXQDA system for analysis, with data from this Focus Group compared to data from other sources, including observations, examination of documents, and Resident Participant interviews.

Participants of this Focus Group received a \$25.00 gift card as an incentive for participation. Additionally, I delivered a personal card to each participant to thank them for helping with the study.

Social Worker Focus Group

One 90-minute Focus Group was conducted with licensed facility Social Workers. This Focus Group also explored the research question: RQ2: *What are the perceptions that staff (direct care workers and Social Workers) have of non-traditionally aged residents living in the LTC setting?*

Recruitment of facility Social Workers was made through an open invitation to all facility Social Workers employed as non-administrative staff. This Focus Group was conducted to capture the general perceptions of Social Workers who directly work with non-traditionally aged LTC residents. No information regarding specific residents was targeted in this Focus Group. As with the CNA Focus Group participants, Social Worker Focus Group participants were sent a pre-Focus Group survey that collected demographic

data and answers to general questions about working with younger residents in LTC settings. Answers to this survey informed the protocol used during the Social Worker Focus Group. This pre-Focus Group Social Worker survey is included in Appendix I and the Social Worker Focus Group protocol included in Appendix J.

All seven non-administrative Social Workers agreed to participate in the Focus Group, which was held across the street from the main facility, in the boardroom of a neighborhood Assisted Living Facility, which is associated with the hospital group that oversees Golden Acres. The Administrative staff, including the Director of Social Services, was supportive of this Focus Group, and allowed the Social Workers to remain *on the clock* for the scheduled two hours, though CNA Focus Group participants were not extended this benefit.

The purpose of the Social Worker Focus Group was to gather information about how Social Workers generally perceive younger residents and whether those perceptions were echoed in observations I made of documents that drive the delivery of services. For example: if younger residents are perceived as disruptive or demanding by Social Workers, are these behaviors addressed in formal assessments and documents of care? Is the delivery of services influenced by the way younger residents are assessed by facility Social Workers?

As previously noted, Informed Consent was discussed at the beginning of this Focus Group, and time was allowed to answer any concerns. The Social Work Focus Group was not digitally recorded, at the request of the Director of Social Services, who stated she wanted to “protect my girls and I don’t want to have to lie if someone asks me if it was recorded.” Detailed notes of the Focus Group were taken by a trained research

assistant, which allowed me to focus on the questions and answers. Participants of the Social Work Focus Group were provided with lunch as an incentive for participation.

I made an analytic memo immediately following this Focus Group, as I sat in the parking lot. As with the CNA Focus Group, notes from the Social Worker Focus Group were open coded at the first reading and later entered into the MAXQDA system for analysis, with data from this Focus Group compared to data from other sources, including observations, examination of documents, and Resident Participant interviews.

Transcription of Data

As previously discussed, recordings and notes from all interviews and Focus Groups were transcribed by me. Although initially, I anticipated using a transcription service, my experience with the pilot study highlighted the importance of remaining close to the data and transcribing the interviews, personally. Although this undeniably added time to the research process, familiarity with nuances in language, pauses in conversation, and inflections of speaking added layers of meaning beyond the words, alone, and would likely have been missed if transcriptions were done through transcription service or software. Further, speaking difficulties experienced by some participants, especially Leonard who lived with advanced cerebral palsy, may have presented difficulty for persons unfamiliar with the study, leading to misinterpretation. Transcribing this data allowed for closer reflection and helped inform analytic memos regarding this process, including opportunities to member check transcriptions and triangulate data.

Analysis of Data

Analysis of data was conducted on a continual and constant basis, following the

constant comparative method, described by Glaser and Strauss (1999/2017), which outlined the iterative building of analysis, beginning with the first piece of data. This process allowed for each additional piece of data to build upon the existing foundation, informing concepts and themes. Initial analysis from each unit of study (Resident Participants, CNA Focus Group, Social Worker Focus Group, Observational data) were analyzed separately, allowing for comparisons between and within groups in this embedded case study. I used open coding during first listens and first readings and used first and second cycle coding to identify common themes from an emic perspective.

All data were analyzed against preliminary research assumptions and study perceptions to answer the identified research questions. The replication in protocols, as explained by Yin (2018), aided in analysis of data sources, including comparisons between, and across, individuals and groups included in this study. Following first and second cycle codings, I analyzed my findings against The Theory of the Looking Glass Self (Cooley, 1902), which allowed an etic analysis of findings to provide analytical generalizations to propositions of an existing theory. To check my analysis, I implemented member-checking with Resident Participants at the beginning of each interview and with all participants at the completion of final analysis.

Coding

The process of coding and the codes I selected corresponded to my interpretivist stance. I believe that what is true is a reflection of what one experiences and the meanings one attaches to those experiences. As such, all reality is subject to interpretation and varies from person to person, place to place.

For this study, transcriptions and observations were used as a method of

discovering the truth of perception regarding the residential experience of non-traditionally aged residents. My use of open coding for first listens and first readings used a process of broad analysis to identify initial impressions of the data, with this open coding setting up signposts that guided my analysis. These signposts served as notices for commonalities and possible trends in data. I also applied open coding of analytic memos and field notes to identify commonalities between what I was hearing and what I was observing. This *chunking* allowed me to identify presenting patterns through a process of extracting data that had “strong associations with one another,” but less association with other elements (Gobet et al., 2001, p. 236).

First cycle codings. Following open coding, analysis of transcripts was conducted using first cycle codings, as recommended by Saldaña (2016). These first cycle codings helped synthesize the data and included *in vivo coding*, *emotional coding*, and *values coding*.

In vivo coding involves coding verbatim, capturing the direct words of the participants (Saldaña, 2016). Words convey meaning and I believe the direct words of study participants is the best way to describe phenomena and experiences. Capturing the direct words of participants is the foundation of an emic approach, which honors the perspective of the individual, situated within the social context. *In vivo coding* captured the unique perspectives of each participant and provided rich descriptions of individual experiences of the persons living and working within the bounded environment of Golden Acres.

Emotional coding involves coding of the recalled emotions experienced by the participants. Emotions are highly tied to one’s perceptions (Zadra & Clore, 2011). The

use of this affective coding helped me remain focused on the key purpose of this study – the description of the residential experience. Zadra and Clore (2011) asserted that emotions and perceptions are tied, with emotions influencing the way persons perceive experiences within the social environment. Using emotional coding revealed data in relation to the research questions. This coding allowed me to understand how the emotions of the participant connected to perceptions of the residential experience.

Values coding involves examining qualitative data to “reflect a participant’s values, attitudes, and beliefs, representing his or her perspectives or worldview” (Saldaña, 2016, p. 131). By using this affective method of coding, I gained a better understanding of the meaning(s) participants attached to events and experiences, especially meanings bounded by the environment. This understanding was key to analyzing the perceptions of the study participants, in relation to their personal attitudes, perceptions, and expectations.

Second cycle codings. Following first cycle coding, I used second cycle coding, including *focus coding*, *pattern coding*, and *process coding*. These second cycle codes built upon each other and allowed triangulation with data gathered from the Resident Participants and Focus Group Participants, as multiple sources of data are at the heart of case study and provide an exploration of phenomena in the natural setting, using the experiences and expressions of persons within those settings.

Focus coding was employed to follow-up prior *in vivo coding*. *Focus coding* allowed me to process collected data from transcripts of Resident Participant interviews and Focus Groups, providing a way to compare coded data from multiple sources. In short, this form of coding allowed me to sift findings from the first cycle, resulting in a

focus of data that was present across multiple sources. This helped guide decisions about the analysis of patterns and themes that developed from the examination of the data (Charmaz, 2014).

Pattern coding allowed for further sifting to look at the patterns that emerged from the first cycle of coding, summarizing the large amounts of gathered data, synthesizing emerging themes.

Additionally, *process coding* was used to assess strategic behaviors implemented by residents to offset the perceptions of staff. What the Resident Participants *did* when faced with negative perceptions became a main focus of this study that emerged, and will be discussed, at length, in the subsequent chapter. Although process coding often takes place during first cycle coding, I had not included it in my original coding scheme. After completion of first cycle coding and reviewing the data, I noted a disconnect between some of the documents of care and some of the data from Resident Participant interviews and Focus Groups. I added process coding to the second cycle of coding to capture these inconsistencies between what people said and what people did.

Software use. I chose to utilize MAXQDA 18.0.0 (2018) software, which provided an ease of analysis between transcriptions, allowing for an examination of both intensity and frequency of the large amount of data. Although I initially planned to analyze descriptive data using SAS 9.4 software, the small amounts of descriptive data were easily analyzed using the Analytics application in Microsoft Excel.

Confidentiality

I implemented additional ways to protect data and confidentiality beyond what was outlined in the Informed Consent Form. Although a breach of confidentiality is a risk

in any study, the risk to confidentiality may be especially keen in this study, which occurs in a closed social environment. This was complicated through the Resident Participants, themselves, who often self-identified as participants. Leonard repeatedly introduced me to others, saying: “Do you remember Sara? I am helping her with her thesis.” Because the study was well-known in the facility, I was often stopped by family members, residents, staff, vendors, and volunteers who were not involved in the study, and who asked questions, such as “How is it going with Leonard?” “Is Mike cooperating with you?” “Let me tell you what happened last week.” Care staff would sometimes knock on doors when I was interviewing a Resident Participant, peeking around the corner to say hello. As previously noted, this level of interest was somewhat annoying to me, but the Resident Participants did not seem bothered by inquiries or interruptions by staff and appeared proud of their participation in the study.

Resident records were encrypted by the facility to assure privacy and were accessible only through facility-supported access and multi-factor passwords. To further protect the collected data, pseudonyms and random numbers were assigned to each of the four Resident Participants and I removed identifying information from documents, transcripts, and other information I collected. All data was stored behind a double lock, in a locked file cabinet located in a locked room.

It is interesting to note that the Resident Participants asked to create their own pseudonyms. All requests, save one, were honored, as I felt unable to identify Leonard by his requested pseudonym of “Dr. Love.”

Confidentiality was less problematic among Focus Groups, especially the CNA Focus Group participants, who requested the group meet off-campus and not be digitally

recorded in order to protect privacy. Focus Group members were also assigned pseudonyms and random numbers, with collected data kept under double lock. Social Work Focus Group participants were also concerned about privacy and requested that the Focus Group not be recorded. When asked about recording, one of the Social Workers, May, stated: “Sometimes, it’s just better for things to be off-the-record. I mean, you never know how the bosses are going to take things.”

All participants were reminded of potential risks to confidentiality through Informed Consent. Additionally, I included statements of confidentiality at the opening of each interview and Focus Group, reminding participants of the importance of privacy and the right to refuse or withdraw from the study. Again, concerns about confidentiality seemed to be dismissed by participants and even the CNAs, illustrated in the following exchange: “Hey, I am Tyrone! What’s your name for this thing?” “Oh, you can just call me Taj”

My reviews of these encounters in field notes and memos illustrated the interconnected relationship between Resident Participants and staff, noting my thoughts that although barriers, locks, and walls may separate institutionalized persons from the larger world, they do not seem to separate institutionalized persons from the institution, or each other.

Conclusion

I selected case research to reliably and dependably describe the residential perspective of non-traditionally aged persons living in LTC settings. The use of an embedded case method is appropriate for collecting evidence to describe phenomena, especially when little is known or when a deeper understanding is warranted. This

dissertation examines a topic that is not well-researched – the residential experience of non-traditionally aged persons living in the LTC setting. In this study, I have used multiple sources of data to answer the identified research questions pertaining to the perceptions of persons who live and work at Golden Acres, including the consideration of alternate explanations for findings. The findings from this study are discussed in the subsequent chapter.

CHAPTER 4

FINDINGS

*As social beings, we live with our eyes upon our reflection,
but have no assurance of the tranquility of the waters in which we see it.*

- Charles Horton Cooley

In this chapter, I describe findings regarding perspectives of the residential experience of non-traditionally aged persons living in LTC settings, including how younger residents feel about living in LTC, how LTC staff perceive younger residents compared to more traditionally aged residents, and how younger residents perceive the way they are perceived by staff. Throughout this chapter, I include themes that emerged from the coding process and how these answered the three research questions. The findings from this study are represented in the three sections of this chapter.

The first section answers the first research question: *What are the perceptions of self for a non-traditionally aged resident in the LTC setting?* I begin with descriptive information about the LTC setting that bounds this study. This section also includes descriptions of each Resident Participant, including a discussion of cumulative disadvantages experienced by the Resident Participants.

The second section answers the second research question: *What are the perceptions that staff (CNAs and Social Workers) have of non-traditionally aged residents living in the LTC setting?* I begin with an exploration of the contrasts between what workers say and what workers do, later discussing how perceptions of staff

influence documents of care and other forms of *material culture*.

The third section answers the third research question: *How does a non-traditionally aged resident perceive the way they are perceived by LTC staff?* In this section I describe how non-traditionally aged residents describe their perceptions of how they are perceived by staff. Moreover, I describe intentional actions taken by Resident Participants to influence the perceptions of staff and improve the delivery of services.

Themes that emerged from this study are discussed throughout this chapter and include:

- 1.) Younger Residents Demonstrate Differentiating Themselves from Other Residents
- 2.) Younger Residents Describe Themselves as Casualties of Capricious Fate
- 3.) LTC Staff Describe No Differentiation Between Non-traditionally Aged Residents and Older Residents
- 4.) Staff Members Appear to “See” Non-traditionally Aged Residents as Makers of Their Own Destinies and Deserving of Their Fortune
- 5.) Non-traditionally Aged Residents in LTC Settings Appear Aware of How They Are Perceived by Staff
- 6.) Non-traditionally Aged Residents Demonstrate the Adoption of Strategies to In an Attempt to Personalize the Way They are Perceived by Staff to Leverage Better, and More Personalized, Care
- 7.) Staff Behaviors Do Not Appear to Consistently Correspond to

Reported Perceptions of Non-traditionally Aged Residents

- 8.) Non-traditionally Aged Residents Describe Seeking Out Social Connections to Personalize the Way They Are Perceived
- 9.) Care is Standardized, Not Personalized
- 10.) Social Connections Appear Preferred over Formal Channels to Leverage Improvement of Delivery of Services

The Setting of the Study

This case study is bounded by the LTC setting. It is here where residents live. It is here where staff work. Like other institutions described by Goffman (1961), this total institution is separated from the larger social world by physical barriers, where entrance is controlled by gatekeepers who provide access to each restricted area. Both Cooley (1902) and Goffman (1961) claimed that social environments, and the proximal social contacts that occur within them, are intertwined and separate from the larger social world. At Golden Acres, this separation begins when I drive onto the property, where a large illuminated sign announces the name of the facility, defining this nursing home as a place of “extended care.”

I turn left in the parking lot and drive past spaces, adjacent to a *cul-de-sac*, reserved for ambulances, coroners, police cars, and vans. Ten parking spaces, reserved for volunteers, border each side of the front parking lot. They are seldom filled, except on Christmas, Mothers’ Day, or Sunday afternoons, when volunteers from local churches provide Sunday School worship. Weekday visitors are rare, except on Tuesdays, when the volunteer named Patty visits. Patty owns a farm and home-schools her two children. On Tuesdays, she brings herself, her girls, and her goats. They walk through the halls,

giving out hugs. Sometimes, Patty brings a large Angora rabbit named Henry, who sits upon a purple pillow in a red plastic wagon, pulled by the girls.

The front parking lot feeds into the back lot, which is where employees park. Seventy-five spaces have recently been repainted wide enough to protect cars and trucks from dents and dings. The Maintenance staff has installed solar-powered security lights that illuminate the lot and the surrounding wooded area. This addition is new, since my employment, and I recall sitting in darkness while waiting for a locksmith to re-key a rental car one long-ago Thursday evening.

There are 420 steps from the back parking lot, to the covered walkway leading to the entrance. A five-foot high, slatted iron fence cordons off the little pond, known as “Snakeville” by some of the employees. Black snakes live around the pond and occasionally slither their way onto the cement patios, located in the lower level of the nursing home. May, the Unit Secretary of one of the units where I formerly worked, keeps a long-running record of snake deaths, both natural and not.

There are 173 steps to the entrance, once the covered walkway is reached. Steps are uphill, at a 10% grade. More than a few carts have freewheeled down this hill, over the curb, and into the parking lot. I worry every time I see a wheelchair, whether coming or going.

About five feet from the front door, is a silver square marked “handicapped push,” mounted on a pink plastered column. The double doors slowly open outward once the square is pushed, except between the hours of 8:00 p.m. and 7:00 a.m., when access to the facility is limited to the secondary entrance, adjacent to the Rehabilitative Center and the Administrative offices. The parking lot near this second entrance was recently

expanded and now has over 200 spaces, which are not quite so wide as ones in the back.



Figure 4.1. Steps to the entrance (English, 2019)

Despite the windows and pink columns, this place is easily marked as a nursing home. The low-roofed, multi-winged building announces its purpose, even without the illuminated sign. The double-doored entry is bounded by a narrow colonnade, with pink stuccoed columns lining large picture windows. There are stone benches on each side of the entry under the colonnade, where families visit, and staff check cell phones during work breaks. At the other side of the door, sits an office, with open windows set into the walls. Linda, the receptionist, greets visitors, asking them to sign in. Linda also transfers phone calls and oversees personal resident accounts. A little sitting area surrounds

Linda's office, where a bulletin board features the monthly activity calendar. A local funeral home often donates flowers; today, bouquets of lilies and roses sit on side tables. The carpeting ends at the entry and the remainder of the facility opens to low walls, floors of beige linoleum, and ceilings of acoustic tiles, with "gold" framed Thomas Kincade-ish oversize prints hanging a little too high for people in wheelchairs to enjoy.

The beauty shop is prominently located, facing Linda's office. A wide hallway lines each of the three open walls of this salon, which has large windows showing some of the female residents receiving wash and set hairdos or Fanci-full rinses of White Minx. A few men usually line up in wheelchairs, in front of the beauty shop, complimenting the ladies' new coiffeurs and noting visitors who come and go. Five years ago, when I was still working here, the Activity Director posted a "No Loitering" sign on one of the beauty shop windows, which the Administrator quickly tore down, reminding the Activity Director that residents could sit wherever they wanted. The gentlemen guard of the beauty shop consider this a victory and now sit there most of the day.

It is pleasant here, at least compared to other nursing homes. It is exceedingly clean. The floor is shined nightly by Gus, a mustachioed Housekeeping employee, who rides the halls on a waxing machine that looks like a small Zamboni. He gently beeps his way across the linoleum, depositing the smell of wax and orange-scented antiseptic. The overhead fluorescent lighting is softened by occasional table lamps and silk plants that sit in the corners of day rooms. Golden Acres is "home" to 286 persons, all of whom require assistance with multiple tasks, including 48 non-traditionally aged residents under the age of 65.

How Do Non-Traditionally Aged Residents Perceive Themselves?

To gain understanding about how non-traditionally aged residents perceive themselves as residents of the LTC setting, I conducted three semi-guided interviews with four selected Resident Participants.

Resident Participants

Four Resident Participants participate in this case study. All Resident Participants are male, ranging in age from 56-62, and admitted to LTC following a traumatic event, resulting in permanent disability. With no person willing nor able to help them care for their needs and no money to pay for care, these men made the only choice available to them at the time -- the nursing home.

Each resident participant has lived in LTC for a considerable amount of time, with the range of residency from 6-44 years, and all expect to live out the remainder of life in care. Table 4.1 provides descriptive/demographic information regarding the Resident Participants of this study, which corresponds with common disadvantages experienced by non-traditionally aged residents living in LTC settings, as previously discussed in Chapters 1 and 2, including permanent disability, low socio-economic status, estrangement from family, and mental illness.

Edgar. Edgar is a 58-year old African American male, who admitted to LTC eight years ago, following a brief admission to the in-patient Rehabilitative Center which is housed within Golden Acres. Edgar's admitting diagnosis is Traumatic Brain Injury, which occurred during an altercation with his nephew who was living in Edgar's home. Edgar was married and divorced once, several years before his admission. He reports that

he and his former wife “talked to” each other when their children were young, with Edgar staying in his wife’s apartment off and on. He has an estranged relationship with his adult son and daughter, although his daughter brings his grandchildren to visit on some major holidays, “once or twice a year or so.” His brother visits a few times per year. Edgar’s sister (and mother of the nephew who attacked him) does not visit and Edgar describes his family relationships as “strained,” though he dropped criminal charges against his nephew several years ago, in an effort to maintain family ties. Edgar has a high school education and worked as a heavy equipment operator prior to his injury, being paid “off the books for years.”

He is morbidly obese and is dependent on staff to complete his needs, including placing him in a sling and using a motorized lift to transfer him from the bed to his wheelchair, or from his wheelchair to the shower. Because of his size and generalized weakness, Edgar has great difficulty propelling and uses his feet to walk his wheelchair, by a process of kicking up the footrests and tippy toeing across the floor, making his way to and from personal activities. A few years ago, he was evaluated as unable to safely operate an electric wheelchair, due to his lack of peripheral vision, which he lost because of the attack. His failure to qualify for an electric wheelchair is a frequent source of frustration for him.

Edgar has limited mobility of his limbs, but uses his right arm to emphasize conversations, gesturing when making a point. He often leans toward me when he has something to share, beckoning me closer with his right hand, calling me “Girl” or “Sis.” He engages readily in conversation and is curious about my research.

Edgar’s medical record notes diagnoses of Mood Disorder and Anti-Social

Personality Disorder, though he does not seem to meet the criteria for the latter diagnosis, appearing affable and humorous and maintaining a few close relationships with other residents. He shares his 360 square foot room with an older, non-verbal bedfast resident. Edgar is often found at the entrance of the beauty shop, commenting on people that walk by – “Girl, I like your shoes!” - or sharing a bag of boiled peanuts with another younger resident.

Leonard. Leonard is a 62- year old white male, who has lived in the nursing home for 44 years, following abandonment by his parents. At the time of his admission, Leonard was noted as malnourished; he reports his family of birth as “abusive” and neglectful. He has lived with cerebral palsy since birth, has difficulty communicating, and is dependent on staff to meet all his needs. He cannot transfer independently and requires two persons to move him from his bed to his electric wheelchair. Leonard stopped going to school following eighth grade but considers himself “very informed,” paying close attention to sports and politics. He starts his day by picking up one of the copies of USA Today delivered to the nurse’s station, “driving” his electric wheelchair to the Rehab Center, where he reads the national news and the sports section during CNN’s commercial breaks.

Leonard’s favorite sports team is the Clemson Tigers and most of his clothing is orange. His Clemson collection spills out of his closet, with his private room lined with pennants, posters, schedules, and foam fingers. He is very proud of his limited-edition Clemson Tiger figurine.

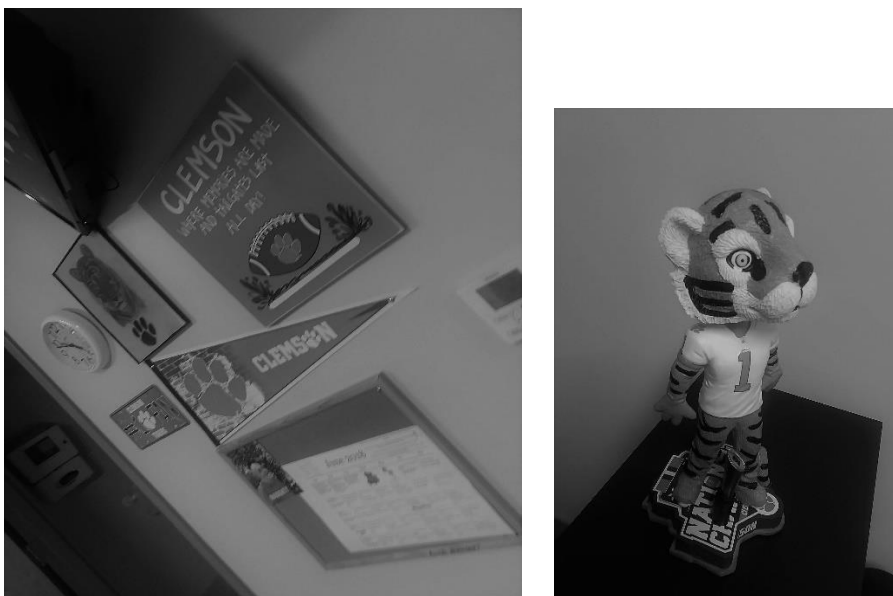


Figure 4.2. Images from Leonard's room (English, 2019)

Leonard has never held a job, never married, and has no children. He has no siblings and both parents are deceased. Recently, a retired couple “adopted him,” taking him out to events and gifting him an electric wheelchair and computer. After several months, Leonard severed the relationship with this couple, who he reported as trying to “manipulate” him to move in with them, change his religion, and allow them to access his medical and financial records. After Leonard severed this relationship, the couple demanded the return of the computer and wheelchair, both of which were replaced by the nursing home.

Leonard's medical record notes a diagnosis of “Mood Disorder, due to known physical condition” and his resident face sheet records “psychological and behavioral factors.” He tells me he is living “on borrowed time” and “should have died years ago,” but he smiles as he says this. He has difficulty speaking and is sometimes hard to understand, but he is patient with those who take the time to listen to him, repeating and spelling words until he gets his point across, laughing and expressing: “Finally!” if it

takes more than a few tries. He reports looking forward to our visits and almost always meets me at the entry of the nursing home before our scheduled interviews.

Mike. Mike is a 56-year old white male and has lived at the nursing home for about six years. He is pale and appears to be frequently distracted. He never married and has no children. Mike entered the nursing home after experiencing a stroke, secondary to drug use, and was unable to return to his home because he could not meet his personal needs. His family was unable and unwilling to assist with his care, and his home was deemed unsafe, due to hoarding.

Though Mike is an experienced attorney, he allowed his license to lapse several years ago, because “I just couldn’t take the continuing education workshops with all those people.” Mike requires full assistance from staff for personal care, including bathing, dressing, and transferring. He reports this dependency as frustrating for him and he sometimes verbally lashes out to staff. He often self-isolates and believes the staff hates him, “possibly due to racially charged comments I have made.”



Figure 4.3. A few of Mike’s pens (English, 2019)

Mike has an electric wheelchair, but primarily stays in his shared room, where he “tries my best to ignore” his room-mate, who is one of Edgar’s close friends. Mike continuously documents the days’ events in a series of Great Value spiral notebooks from Wal-Mart, which he pronounces “The. Best.” Mike’s mother is deceased, and he is estranged from his father. His only sibling, a brother and local physician, visits a few times a year, “whenever he feels guilty enough.” Mike describes the relationship with his brother as “less than tolerable.”

Mike’s medical record notes a diagnosis of a “Mood Disorder” and “Schizophrenia” and he presents as cautious and guarded. He seems to enjoy one on one conversation and waves at me as I knock at his open doorway. During one of our interviews, we sat in the colonnade at the front entrance and he shared that this was the first time he had been outside of the building since before his admission. Mike welcomes me at each visit and shares a special notebook he keeps, documenting our time together.

Walter. Walter is a 62-year old white male. He admitted to the LTC setting eight years ago, in 2011, following a stroke of unknown origin. Walter never married and has no children. He describes his relationships with his family, which includes his father, brother, and sister, as “nearly non-existent,” though he maintains relationships with several life-long friends through Facebook. Walter has lived with cerebral palsy throughout his life and is dependent on staff to meet his needs, including a two-person transfer, to and from his bed. He uses an electric wheelchair to attend personal events, but spends most of his time, in his bed, reading Louis L’amour westerns on his Kindle or communicating with friends, through social media. Walter earned an Associate Degree at a local community college and spent several years working as a dispatcher with a local

sheriff's department, "until a new guy was elected."

Prior to coming to the nursing home, Walter lived in a renovated travel trailer, parked in his parent's back yard. He likes his solitude and has lived for several months without a permanent roommate, accomplishing this by being what one Social Worker describes as "just unpleasant enough" to encourage room-mates to request relocation. Walter has lived through several surgeries and likes to show me his scars, including the newest one from a heart bypass, which he traces across his chest as he sits in his bed, surrounded by several paperback books, his Kindle, and a cell phone.

Walter's medical record notes a diagnosis of "Mood Disorder and Paranoia." He always greets me with a smile and often openly participates in the study; however, when he does not want to answer a probing question about his personal life or history, he tersely states: "it just didn't work out." His dispatching job "just didn't work out," his college degree "didn't work out," his relationship "didn't work out." When I ask *what* didn't work out, he looks at me and says: "It... just... didn't... work... out."

I connect easily with these participants, who seem eager to share their stories. All of them report being pleased to participate, both to me and to their Social Workers. All of them have requested a copy of my dissertation. Additionally, Mike has made requests for a pen with a USC logo.

Table 4.1 *Participants – Demographic Information*

Resident	Age	Length of Admission	Gender	Race	Admitting Diagnosis	Primary Diagnoses	Funding	Family Connection
Edgar	58	8 years	Male	A-A	CVA	Anti-social disorder; anxiety; delirium; paralysis secondary to trauma; visual impairment	Medicaid	distant
Leonard	62	44 years	Male	W	Severe malnutrition	General Anxiety Disorder; Major Depression; paraplegia, secondary to cerebral palsy; Irritable Bowel Syndrome	Medicaid	absent
Mike	56	5 years	Male	W	CVA, secondary to drug use; delirium	Major Depression; psychosis; paraplegia, secondary to CVA; Chronic ethanol abuse	Medicaid	absent
Walter	62	8 years	Male	W	CVA	General Anxiety Disorder; Major Depressive Disorder; Paranoia; COPD; paraplegia, secondary to cerebral palsy	Medicaid	distant

Interview Process with Resident Participants

As previously discussed, it was difficult to find private spaces to conduct interviews. Leonard lives in a private room, so his interviews were conducted there. Walter is continually “in-between roommates,” and because he was what he called *sans room-mate* during all of my visits, his interviews were also conducted in his room. Edgar and I met in an unused conference room, which had been reserved by the Administrative staff; but it was always difficult finding a private space to meet with Mike. Mike shared his room with a room-mate, who “likes to listen in.” He expressed feeling uncomfortable outside of his unit. On one occasion, we met in an empty therapy room in the Rehab Center and were continually interrupted by staff who, despite locked doors and Do Not Disturb signs, repeatedly unlocked the door, apologized, and grabbed equipment, saying they “would only be a minute.” Mike doesn’t like the conference rooms and expresses that “they are probably bugged.” As a result, we held each interview in a different place: a treatment room, a dining room, the entry, with each location interrupted by staff gathering equipment, retrieving files, or in one case taking a short cut through the room, from one unit to another. Mike shrugs and notes that “people are always around,” but he looks over his shoulder every time we are together and speaks in hushed tones.

As discussed in Chapter 3, I began each interview with a recap from the preceding interview, reviewing my preliminary assessment of transcripts, asking Resident Participants if my analysis was correct. I feel this question and answer period helped establish and maintain trust. It also helped bring the Resident Participants *in* to this study, which is essential to the emic approach. I also invited Resident Participants to ask any questions regarding previous interviews, though they rarely had questions. When

questions were asked of me, they were often personal: How long was this going to take to write? What did I plan to do after I was finished? When would I graduate? Edgar seemed to echo my own thoughts one day, asking: “I wonder if you are ever going to get done with this thing?” My analytic memos from that day read: “No kidding.”

I recorded the interviews, using a digital recorder application, available through Googleplay.com. Following each interview, I made analytical memos of my visits, as soon as possible, usually making memos as I sat in my car in the back parking lot. I transcribed each interview as soon as possible, but prior to coding and analyzing the data, I open coded the recordings through a first listen, where I concentrated solely on my impressions of the data. Transcription proved difficult for my interviews with Leonard. Due to his difficulty with speech, they involved a lot of listening, rewinding, listening again, rewinding, editing, and listening once more. At one point, I tried to send a recording of Leonard to a transcription service, which reported the recording as: “Unintelligible. Unintelligible. Unintelligible.” Following this, I returned to my earlier method of transcription, reminded of Leonard’s patience with me and his desire for me to fully understand him. I found myself, like Leonard, exclaiming “Finally!” when his words became clear.

Findings from Resident Participant Interviews

Below, I describe some of the findings that help answer the first of my research questions, which focus on how younger residents perceive themselves as a non-traditionally aged person living in LTC. As previously discussed, Informed Consent was provided at the beginning of the first session. Demographic information was confirmed at this time, as well.

Theme # 1: Younger Residents Demonstrate Differentiating Themselves from Other Residents

To answer the first research question: *What are the perceptions of self for a non-traditionally aged resident in the LTC setting?*, I asked each Resident Participant to describe how he viewed himself, as a younger resident, living in the LTC setting. All Resident Participants shared unique things about themselves. Mike practiced as an attorney. Walter traveled across Europe, singing with his college choir. Edgar operated heavy machinery, including steamrollers and backhoes. Leonard had the unique ability to recall long sequences of numbers. Despite their unique experiences, the men shared common characteristics of non-traditionally aged LTC residents, as described in current research (Centers for Medicare and Medicaid, 2016; Harris-Kojetin et al., 2013).

- **All Resident Participants are permanently disabled** and dependent on staff for most ADLs, including bathing, dressing, eating, grooming, toileting, and transferring.
- **All Resident Participants receive Medicaid and have no additional sources of income.** Edgar and Mike earned money “off the books” through illicit behavior, prior to entering the nursing home, with Edgar reporting spending “a night or two in jail.” None of the Resident Participants had private insurance and all were too young to receive Medicare. The lack of supplemental income limited choices for these men and was a primary factor leading to their admission to the nursing home. Since admission, the

Resident Participants have had care fully-funded through Medicaid. Each receives a \$30.00 monthly allowance, which they use to pay for personal purchases, including boiled peanuts, Comer's popcorn, and *adult* films, streamed through online services.

- **All Resident Participants experience some form of social estrangement**, with none of them reporting positive relationships with their family of origin, and either absent (no contact with family members) or distant (inconsistent contact, no more than three times per year) relationships. Only Edgar reports children, from whom he is essentially estranged. Edgar is also the only Resident Participant who has married, though that marriage ended in divorce several years prior to his admission. Leonard, Mike, and Walter have never had a committed romantic relationship, although "I certainly had more than a few ladies," was spoken, more or less verbatim, by both Walter and Mike.
- **All Resident Participants are diagnosed with mental illness(es)**, ranging from Generalized Anxiety Disorder to Paranoid Schizophrenia, with these diagnoses appearing on admitting documentation from hospitals, indicating that, for these men, mental illness preceded admission to LTC. All of them are under the supervision of the facility's

contracted psychiatrist and are prescribed psychotropic medication on a regular and PRN basis.

These characteristics – permanent disability, low SES, social estrangement, and mental illness – can be viewed as cumulative disadvantages (Wolff and de-Shalit, 2007) that cluster together and lead to LTC admission, as previously discussed in Chapter 1. Despite shared characteristics to each other and to other non-traditionally aged residents, the Resident Participants emphasize that they are not like what Walter calls: “those *other* people who live here” and persons Leonard describe as “crazy,” or “confused;” and those whom both Edgar and Mike note as “helpless,” or “pitiful.”

The Resident Participants seek differentiation through a form of self-othering, comparing themselves to others and noting why they are unique. “I would say I am the perfect example of Edgar (laughter). Yeah, ain’t nobody like Edgar!” Edgar responds, when asked to describe himself. “I am pretty sure nobody had a life like mine,” expresses Leonard. “I get along here better than anyone else. I mean, I’ve been here longer than anyone else. Everyone else is pretty pitiful.” Walter, too, expresses his uniqueness, noting: “You know, everyone wants to put you into some kind of pigeon-hole, but I don’t fit. I’m not like the other residents.”

For Resident Participants, differentiating themselves from other residents is burdensome. Mike expresses frustration: “I am always reminding people that I am not one of these old people. I don’t like the food that old people like. I don’t want to go to bed right after the news.” This exchange with Leonard outlines a bit of this difficulty:

Leonard: *Every time some new nurse comes on, I have got to introduce myself and tell her my story.*

S. English: *What do you mean, you have to tell her your story?*

Leonard: *Oh, you know... I have got to tell her how I came here, how long I have lived at Golden Acres. I have to let her know I know things and that I am not like all the other people in a wheelchair. You know, I have to tell her about me.*

Differentiation also presents opportunities. Edgar, Leonard, and Walter expressly report feeling responsible for those who are unable to speak for themselves and actively advocate on behalf of those they view as less able, seeing this as a meaningful role. In the following exchange, Edgar reports “rolling around” and checking on others.

Edgar: *Look, I've got to live here. I watch stuff, though... I make sure things get done.*

S. English: *Do you see that kind of, as your role here?*

Edgar: *Yeah, definitely. A lot of people don't like you if you do that... you probably know that, but I look and say, what about my room-mate? He can't talk, okay? I say "I don't think he's OK... What's wrong with y'all?" Another lady...what happened is she was feeling very cold and they need to cover her up with a quilt or something... And I know it's cold over here. I tell 'em, she's gotta be cold.*

Walter is quick to explain the difference between him and “the other residents,” noting a feeling of responsibility for others, saying: “I’m not like the other people here. They are sick and they need someone to look out for them. I help them do things, play Bingo, sing... and I let the nurses know when something is wrong.” Leonard also reports a sense of duty toward “the others,” saying: “Most of the other people who live here are pretty helpless... I know what’s going on, though. They (the staff) know it, too. I let the big bosses know if something’s up.”

As Walter states:

*I don't have my legs, but I still have
my brain and I can use that to help
somebody else... And I've been
depended on to help some others,
who can't see well or can't get to
their (Bingo) cards and I help them
out.*

Theme # 2: Younger Residents Describe Themselves as Casualties of Capricious Fate

My quest to further explore the first research question prompted me to ask questions about how the Resident Participants viewed themselves, particularly because they were all in developmental stages that encompass what Perlman (1979) described as a broad swath of time, during which persons establish and maintain families and careers. I sought to describe how these men perceive this thwarting of both family and career, during the developmental stages of Young and Middle Adulthood (Erikson, 1950/1963).

My initial interviews with the Resident Participants gathered background data, which I later compared to intake assessments prepared by facility Social Workers. Of the four Resident Participants selected for this embedded case study, all reported experiencing long-standing and multiple economic, educational, physical, psychological, and social disadvantages prior to their permanent admission to the LTC setting. Edgar notes: “Girl, I have always been poor. I’ve had to fight for everything.” Leonard shares:

“It’s been a life-long thing. I have never been normal. I was born to it.” Mike, who had been a licensed attorney, struggled with “some mental problems” most of his life, which affected his stability economically, socially, and professionally. Walter discusses how the intersection of disability and poverty created difficulty for him over his lifetime. Each participant reports experiences with poverty and dependency upon Medicaid as the funding source for care, both pre- and post-admission. Each resident experiences at least one permanent disability, with half describing a long-term disability present prior to admission, which was not related to the reported admitting diagnosis noted in the medical record. Each resident has a diagnosis of at least one mental illness or personality disorder noted in the medical record, though not every resident participant agrees with this diagnosis. Every resident is assessed as “cognitively intact” by the facility Social Workers and acts as his own responsible party for healthcare and financial decisions, though neither Edgar nor Leonard has a designated proxy, who would make these decisions, in the event that such decisions were needed.

Every Resident Participant reports experiencing multiple disadvantages; yet, these disadvantages are described as what Walter calls “fate,” what Leonard notes as “what life gave me,” and what Edgar describes as “the roll of the dice.” Despite the reported cluster of disadvantage, no resident participant connects their experiences with disadvantage(s) to their LTC admission; rather, they view admission to LTC as a result of a random one-time event, such as a stroke, an accident, or an assault.

Edgar arrived at the nursing home, following a long hospitalization after an assault by a nephew. The nephew lived with Edgar in a small rented home, along with Edgar’s sister, who was the nephew’s mother, and “a couple of other people.”

Edgar describes the event in this interchange:

Edgar: So, I had come home from work. It was late, you know? I was a little high and he was, too. He was out in the yard, cranking the music in the car... And the music was loud, really loud. The landlord's right next door. I say to him that it's late. He's high and don't answer, so I ask him again. We're yelling now. I go and pull the keys out of the car, so the radio will cut out. He's yelling some shit. I just want to go to bed. I go to step up to the door and BOOM!

S. English: Boom? What happened?

Edgar: I don't know. I hear this sound whizzing past my head and BOOM! Next thing I know, I'm in the hospital.

Fucker hit me with a brick.

Edgar was beaten about the head, resulting in traumatic brain and spinal cord injury, causing paralysis and the loss of vision in his left eye. Edgar does not remember the event past the BOOM!, but he describes his time at the hospital and the Rehab Center. He also talks about “them carting me across the breezeway, to here.” When asked what he thought led to his admission, Edgar shrugs, beckons me forward with his right hand, and states: “Anything can happen. It came out of nowhere, you know what I mean? That kinda shit can happen to anyone.”

Leonard, who lived the whole of his adult life in care, nonchalantly reports: “I got sick, they couldn’t take care of me, they dumped me off. Whatever.” When asked if he thought any of his life experiences led to his admission, Leonard shakes his head. “No,” he says. “Stuff happens, you can’t really predict it.” He straightens up in his wheelchair and points to me: “You could be walking down the street and a car hits you, you end up here. That’s what happened. I didn’t get hit, but you know, it happened, and I came here.”

Mike, who has lived at the nursing home for a little over six years, echoes this, stating that he had a stroke because he “got bad drugs. What are you gonna do? Shit happens.”

The lack of social support influenced the LTC admission decisions of the Resident Participants. Edgar had been assaulted and his nephew charged with the crime, which resulted in the separation of family members, who “picked sides,” determining who was right or wrong. Leonard had experienced extreme neglect and violence at the hands of his parents, who abandoned him on his 18th birthday, leaving him and “a couple

of boxes” at the entrance of Golden Acres. Mike “lived like a hermit” and though he had a girlfriend, prior to his admission, she broke off their relationship shortly afterwards, “leaving me to myself, again.” Finally, Walter, lived in an old travel trailer, “in the back forty” on his parents’ land, but had little contact with his family, maintaining what he called “safe” relationships with friends through Facebook and email. “They had no interest in helping me when I got out of the hospital,” says Walter.

The Resident Participants describe their admission to LTC as a logical result of dramatic and unexpected one-time events, over which they had no control. Edgar frequently notes his assault and further explains his story, leaning forward in his chair and recalling the assault by his nephew, again:

*It came out of nowhere, unexpected.
My nephew, he was out there, he was
on dope. We live next door to my
landlord and we had an old wooden
house. Nice place. He put on his
music in the middle of the night, 4:30
a.m. I don't, I don't have the mood. I
went and turned off the music... By
the time I reached the door, I heard
something go past my ear, like it
wasn't no more than about one
inch... then, when I woke up in the
hospital, I couldn't move.*

Although Mike experienced a stroke, secondary to persistent drug use, he sees no connection between this and his admission and, instead, views his stroke as a disconnected event, stating: *“I came here because I had a stroke, that’s the reason.”*

Though all Resident Participants experience the clustering of disadvantages, previously noted as the primary reasons for LTC admissions, none of the Resident Participants describe a connection between persistent poverty, substance use and dependency, risky behaviors, chronic conditions, criminal activity, or the absence of social support as a reason for their admission to LTC. They believe that previous experiences and life choices has not destined them for admission to LTC; rather, it is the result of what Edgar called “the flip of a coin.” For these men, chance, not choice, had brought them to the LTC setting.

How Do LTC Staff Perceive Non-traditionally Aged Residents?

To gain understanding of how staff perceive non-traditionally aged residents living in the LTC setting and answer the second research question: *What are the perceptions that staff (CNAs and Social Workers) have of non-traditionally aged residents living in the LTC setting?*, I conducted Focus Groups with CNAs and Social Workers. Participants of these Focus Groups self-selected for the study; however, only those who met the study criteria were invited to participate in the Focus Groups.

The protocol for each Focus Group was similar, however questions were targeted for the particular role the participants filled in the LTC setting. Additionally, some protocol questions were framed by answers provided through pre-Focus Group surveys.

Focus Group Participants

CNAs. Six CNAs participated in the Focus Group. As previously discussed, it was very

difficult to arrange a Focus Group for CNAs. Many voiced a lack of interest, as a Focus Group added to their already burdened schedule. Sandra, who I had known from my working days at Golden Acres told me, “Sara, you know I would love to help you out. I just don’t have any time. There is so much to do and I can’t add one more thing.” Those who expressed interest worked across the shifts and scheduling a time when all could be available was complex. At one point, I thought I would have to abandon the Focus Group for interviews; however, after many phone calls and texts, a mutual time, away from the facility, was arranged. The CNA Focus Group consisted of four females and two males. The females had worked at the facility between 5 and 22 years. One male CNA had been a long-time employee and the other male was working as a CNA, while pursuing a nursing degree, under the facility’s Aide-To-Nurse program. The CNA group was diverse in age and race. Table 4.2 depicts demographic data for the CNA Focus Group.

Social Workers. Seven Social Workers participated in a Focus Group. This group was easier to schedule as the Administration supported this group by providing paid time to participants, allowing them to remain *on the clock* for the two hours devoted to the session. All Social Work participants were female and had worked at the facility for over one year, with employment at this LTC setting ranging between one and 21 years. The group was diverse in age and race. Table 4.2 also depicts demographic data for the Social Worker Focus Group.

Table 4.2. *Focus Group Participants – Demographic Information*

Certified Nurse Aides (CNAs)							
Name	Gender	Age	Race	Role	Certification	Length of Time in Profession	Length of Time at Golden Acres
Brenda	F	32	W	Care	CNA	12 years	10 years
Cynthia	F	52	W	Care	CNA	22 years	22 years
Larry	M	47	B	Care	CNA	12 years	7 years
May	F	37	B	Unit Secretary	CNA	12 years	9 years
Taj	F	26	B	Care	CNA	5 years	5 years
Tyrone	M	24	L	Care	CNA	1 year	1 year
Licensed Social Workers							
Amanda	F	43	B	Social Worker	MSW	6 years	4 years
Brenda	F	42	B	Social Worker	MSW	16 years	11 years
Cindy	F	49	W	Social Worker	MSW	22 years	21 years
Holly	F	40	W	Social Worker	BSW	17 years	15 years
Linda	F	24	W	Social Worker	MSW	1 year	1 year
Maria	F	38	L	Social Worker/ Psychiatric Liaison	MSW	8 years	5 years
Susan	F	57	B	Social Worker	MSW	8 years	6 year

Findings from Focus Groups

Prior to the scheduled Focus Group sessions, I sent a Pre-Focus Group Survey to all Focus Group participants (Appendix G depicts the pre-focus-group survey for CNAs; Appendix I depicts the pre-survey for Social Workers). The answers to the respective surveys informed the protocols for each respective Focus Group (Appendix H depicts the protocol for the CNA Focus Group; Appendix J depicts the protocol for the Social

Worker Focus Group.) As previously discussed, Informed Consent was provided at the beginning of each Focus Group. Below, I describe some of the findings that helped answer the second of my research questions, which focuses on how non-traditionally aged residents living in LTC settings are perceived by staff.

Theme # 3: LTC Staff Describe No Differentiation Between Non-traditionally Aged Residents and Older Residents

To answer the second research question: *How do workers in LTC perceive non-traditionally aged residents living in the LTC setting?*, I asked Focus Group participants to broadly describe their impressions of non-traditionally aged residents. Both CNAs and Social Workers overwhelmingly state that the needs of younger persons and older persons are the same. Brenda, who has worked as a third shift CNA for over ten years, shared:

It doesn't really matter if they are young or old, you still need to help them get up, go to the bathroom, get dressed, eat, everything. Everybody who lives here needs help with everything. Young, old, doesn't matter. Everyone deserves to be treated right.

Tyrone, a 24-year old nursing student, working as a CNA, agreed: "Everyone needs something, you know? Everyone is stuck here. They all need help."

When this question is posed to the Social Workers, Maria, who has worked at

Golden Acres for over five years, crosses her arms and leans back in her chair, noting: “A resident is a resident.” The theme of all residents being the same was rarely challenged. An exchange between Holly, a Social Worker who had worked at the facility over 15 years, and Linda, the most recently hired Social Worker at Golden Acres, illustrates the power of influence regarding this perception:

Holly: *I don't see younger residents as any different than older ones. They all want something and need something, they are not any more aggressive or needy or anything else.*

Linda: *But, how does that see them as individuals? Doesn't everyone have their own personal needs? Shouldn't we pay attention to individual things they might need or want?*

Holly: *No. You can't be fair, unless you treat everyone the same.*

Linda: *** Did not respond nor participate further***

For staff, differentiation does not individualize care, but promotes “unfair” treatment, and all residents should be treated the same. Cynthia, a long-time CNA, notes: “I can’t know everything about everyone. I just make sure I treat them all good. If I treat everyone the same way, then I am doing a good job.” Tyrone agreed, adding: “It’s just the right thing, isn’t it? If everyone is treated well, then everyone is good.”

These *in-person* answers mirrored answers from the pre-surveys, where Focus Group participants deny they perceived non-traditionally aged residents differently from older residents; however, this finding conflicts with answers to other Focus Group questions, which led to the next theme.

Theme # 4: Staff Members Appear to “See” Non-traditionally Aged Residents as Makers of Their Own Destinies and Deserving of Their Fortune

To further explore the second research question, I asked a series of questions that focused on how staff perceived non-traditionally aged residents, including why participants thought the number of younger residents was increasing. Cynthia, who has worked as a CNA for over 20 years, leans across the table and comments: “Well, they make a lot of bad choices, don’t they? Drugs, crime... they end up here after things go wrong.” Larry, a CNA of many years, notes: “What else would happen? You play with fire, you get burned.” Brenda, one of the informal CNA leaders who is known as “Little Brenda” to differentiate her from the Brenda who worked as a Social Worker (“Old Brenda”) and the Brenda who worked as a Housekeeper (“The Other Brenda”), led a group discussion with this:

Brenda: *What's that old
saying? If you lay
down with dogs...*

Group: *You get up with fleas*
laughter

Facility Social Workers voiced similar perceptions, as the following exchange illustrates:

Maria: *I see them (younger
residents) coming in,
mostly because of
earlier decisions.*

Cindy: *Like, they choose to
do things, you know?
They choose to do
drugs, then they have
a stroke.*

Maria: *Or they hang out with
bad people. Some of
them have been shot.
It's not like they are
really sick... they did
something that led to
them coming here.*

Brenda (“Old Brenda”) sums it up this way: “Look, if I choose to do stupid things and something happens to me, then it’s my fault, right? Same with them. They did stupid things and got caught. That’s why they’re here. Stupid things.”

This finding conflicts with the answers CNAs and Social Workers provided on Pre-Focus Group Surveys and earlier statements, which focus on the theme that all residents deserve to be treated the same. Staff note the primary reasons for LTC admissions of younger persons as closely linked to residents’ behavior and choices prior to admission, including substance use, risky behaviors, and criminal activity. Staff overwhelmingly express the perception that, in general, non-traditionally aged residents enter the nursing home due to bad choices, which logically leads to bad outcomes, such as traumatic injuries that could be avoided.

For LTC staff, choice, not chance, determined why non-traditionally aged persons admitted to the LTC setting.

How Do Non-Traditionally Aged Residents Perceive That They Are Perceived by Staff?

To gain understanding and answer the third question: *How does a non-traditionally aged resident perceive the way they are perceived by LTC staff?*, I asked specific questions regarding how younger residents thought workers perceived them. This series of questions took place during the second and third interviews with Resident Participants. Findings from these interviews informed the next theme.

Theme # 5: Non-traditionally Aged Residents in LTC Settings Are Apparent Aware of How They Are Perceived by Staff

In the second and third interviews with each Resident Participant, I asked a series

of questions about staff perceptions of younger residents. The Resident Participants are very clear about how they believe they are perceived by staff. Edgar is quick to respond to questions about staff perceptions. He looks over his shoulder, leans toward me, and says: “Girl, I know how they see me. They think I am a loser and that I got what I deserved... You know, it's very hard... you can be here, you know every day, but really, they don't know you at all.”

Mike agreed: “The staff thinks we’re stupid, like everyone else. They think we are confused or something, at least they treat everyone like they do. They forget that I still have my mind. They think everyone who lives here is crazy. Like, you deserve to be here or something.”

Walter expresses frustration, when describing his thoughts about the way he was perceived by others:

The staff lumps everyone together, in one big lump. Everyone is crazy, everyone has lost it... When you live here, sometimes people don't hear you, you're discounted as being retarded or just not working... sometimes you find staff that are just willing to do their job, but that's it. They don't want to have any kind of interaction with you at all, you're not considered a person. You're not considered a value to them. And that...that... that's one of the hardest things for me to deal with... the staff not, not caring about you.

Unlike staff members, who note same treatment as equal treatment, the Resident Participants view same treatment as depersonalizing, with Mike noting: “They really just think everyone in a wheelchair is confused. I’m in a wheelchair, but I’m not crazy.”

For non-traditionally aged residents, being treated the same as everyone else, means being dismissed as an individual and treated, literally, indifferently, by LTC staff. This perception led to an additional finding, described below.

Theme # 6: Non-traditionally Aged Residents Demonstrate the Adoption of Strategies to Personalize the Way They are Perceived by Staff and Leverage Better, and More Personalized, Care.

I followed-up questions regarding perceptions of staff, reported by Resident Participants. These follow-ups were not scripted but served as prompts to encourage deeper understanding and clarity regarding resident participant’s perspectives about the perspectives of others. Prompts utilized interpersonal interview skills, such as “tell me more about that.” Responses to earlier questions informed my probes, as in this exchange with Edgar:

Edgar: *Look, I know what they think
of me, so I gotta be smarter.*

S. English: *What do you mean,
“smarter?”*

Edgar: *Well, like, I gotta work a little
bit, you know? I gotta get
them to know me, as a
person, not just some guy in a
wheelchair.*

S. English: *So, how do you do that?*

Edgar: *So, what I decided to do is go
and eat with them. Yeah, I go
and get some of my money
and go across the way and
get my lunch, there. I sit in
the dining room and eat with
the workers. I ask them
things, you know... What's
up? How's your kid? You
feeling all right?*

S. English: *In the dining room? You do
this in the dining room?*

Edgar: *Yeah, the dining room, where
the workers eat. I motor over
there.*

S. English: *Who do you sit with?*

Edgar: *Whoever is around, doesn't
matter... Maintenance guy,
CNA, somebody from the
office. I just sit and ask them
stuff.*

S. English: *Why?*

Edgar: *Girl, people don't treat you*

*like nothing, if they know
you. I am known. People that
know me treat me better.*

S. English: *Like, how do they treat you
better?*

Edgar: *Maybe I get some slack.
Maybe I get to sleep a little
later... or get an extra piece
of cake. People just treat you
better if they know you, for
you.*

Edgar is not alone in this strategy. Leonard and Walter also report eating with staff as a useful way to leverage more personalized care. These three men report using money from their limited monthly allowance of \$30.00, to buy food in the staff canteen. Edgar has also successfully lobbied for a discount of 20%, which was recently extended to all residents. “They give me free tea, too!”

The trip to the canteen is not easy and involves going to the front lobby, requesting a withdrawal from one’s personal account, waiting for the processing of the withdrawal, accessing entrance to the breezeway by pushing the sensor pad located on the left side of the hall, crossing the 250 foot span and accessing the exit by pushing another sensor, crossing the Administrative offices, turning to the right and proceeding down a 300 foot hall, turning left and going down another 300 feet to another locked entrance, with the sensor pad located on the right, backing up one’s wheelchair to allow for

clearance of the electronic door that opened outward, making a very sharp left turn into the dining room, and waiting. Edgar explains that residents are only allowed in the dining room of the canteen and are restricted from entering the cafeteria line:

When I get there, I can't go in, because of the chair. It's too big, so I gotta wait for someone to come and take my order. I used to have to wait a long time, but now it's pretty quick. Someone comes and takes my order and my money and brings me my tray.

Walter explains his dining room visits as an investment. "I go and people see me, they talk to me, they get to know me. It's hard to mistreat someone you know." The Resident Participants intentionally work to establish social connections with staff who are perceived to have power, whether that staff works directly with them, or not. The Resident Participants seek out workers perceived as helpful or likely to influence staff members assigned to the unit where they live.

For example, Edgar visits the physical therapy room if he wants someone to purchase a lottery ticket for him, as this same request has been rebuffed by the Activity Director who works on the unit where he lives. "I know who to ask," he says. Walter often engages the Social Worker of an adjacent unit whenever he has a request, because he finds his assigned Social Worker unhelpful, noting: "If I tell her (the alternate Social Worker) something, or ask for something special, I know it will get done. Never sure with the other one." Leonard uses his social connections, established over many years and many moves between the various nursing units of Golden Acres, counting on his

relationships to provide a more rapid response to his requests.

I am good and friendly with the head of Maintenance. Anytime I need something fixed, it gets fixed. If I have a problem with the cable, one of the Maintenance guys comes in and takes care of it. They know me, so they help me when I need it.

Leonard, who is the only permanently admitted resident living in a private room, makes efforts to maintain a good relationship with the facility Administrator to keep his private space. He continues:

I was really worried when the new Administrator came. The old Administrator had made sure I had a private room in the rehab unit, and I was pretty sure I would be moved back to the regular part (of the nursing home). When the new lady came, I made sure she got to know me, just in case. I told her my sad story and how I never had my own place until I came here. They move people all the time, not me. Still got it!

waves his arm, indicating his free space

Walter notes his relationship with the Director of Activities as a way to improve

the delivery of services. He explains this relationship as a “Just in case,” saying: “I look over the calendar every month and figure out ways to help out... Bingo, leading Sunday School... if I ever need anything, I can ask her, and she will see that it gets taken care of.”

The Resident Participants accurately assess how they are perceived by staff and intentionally engage in ways to enhance perceptions by others. Additionally, most seek out relationships with persons in positions of power, utilizing those relationships to leverage better, and more individualized, care.

How Does Observational Data Correspond to Findings From Interviews and Focus Groups?

To develop a broader understanding of this embedded case, multiple points of data were analyzed, including observational data gathered from field observations and the examination of facility documents, such as Behavior Books, BIMS tests, EMRs, and quarterly assessments. This data was explored to determine consistency (or inconsistency) between reported perceptions regarding non-traditionally aged residents in the LTC settings and observed behaviors of CNAs and Social Workers. In other words, I wanted to compare what people said to what people did. This led to the development of the following theme.

Theme # 7: Staff Behaviors Do Not Appear to Consistently Correspond to Reported Perceptions of Non-traditionally Aged Residents

As discussed in Chapter 3, I gathered Observational Data in addition to data from Resident Participant interviews and Focus Groups. To learn more about the day-to-day interactions between non-traditionally aged residents and staff, I conducted six, two-hour

observations and examined various forms of *material culture*, unique to this setting, such as Behavior Books, Communication logs, and newsletters. I wanted to know more about what staff *did*, not just what they *said* they did. What were the actions of the staff regarding younger residents? Did these actions mirror reportings from Focus Groups?

I observed common entry areas, watching how residents are greeted as persons come and go, and where access to the outside world was gained by pressing a silver button, about seven feet up the wall that framed large picture windows. It struck me how inaccessible this button was each time I had to stand on tiptoe to engage it.

I watched large group activities that occurred in the cavernous Activity Center, a large, uncarpeted, echoing beige box, centrally located on the first floor, where residents listened to second-grade choirs or Country-Western karaoke. I spent the largest amount of time observing day rooms and other common areas, with additional time spent at nurses' stations, where staff often gathered. Observations conducted at nurses' stations offered clear views to common day rooms and hallways and allowed me to observe interactions between the residents and staff, residents and other residents, and staff and other staff. Field notes were kept for each observation and analytic memos were made following each observation, and later uploaded. Observations were initially open coded to allow for broad analysis of patterns and later coded through the same process as data gathered from Resident Participant interviews and Focus Groups.

Despite what was said in the Focus Groups, CNAs and Social Workers do not treat non-traditionally aged residents in the same manner as older residents. Interactions seem less personal between younger residents and staff, with CNAs appearing to spend less time interacting with younger residents during mealtimes and activities. Younger

residents are frequently passed in hallways without verbal acknowledgement. I was surprised to find that one of my field notes documented staff passing younger residents in the hall 17 times, over a two-hour period, without acknowledgement.



Figure 5.1. View from the nurses' station, Leonard's unit (English, 2019)

This behavior is noted by Mike, who describes feeling shunned by staff, due to an incident that occurred early in his admission:

I got mad and I made some racial remarks. It was stupid and I was really mad. I guess word got out because none of the aides bother to speak to me about anything. They pass me by, without saying a word. Happens every time.

Indeed, it does happen every time I walk beside Mike, as we move from his room

to wherever we are using as an interview area. At no point, either going to or from Mike's room, does a staff member greet Mike. This is in sharp contrast to older residents who live on the nursing unit where Mike resides, and who I witness being called by name, touched on the shoulder, and hugged by staff as they are passed in the hall.

Less time appears spent providing personal care to non-traditionally aged persons compared to older residents, regardless of complexity of care. Although this observation is highly subjective, and I do not know the reasons or level of care being provided, I notice Care staff spending more time helping older residents than younger residents. Notes from observations I made while sitting at one of the nurses' stations read: "Staff walks by younger person on the way to shower room. Staff walks by younger person as they pass fresh water pitchers. Activity Director invites three older residents to music; younger resident sitting close by not invited." Additionally, assistance for younger residents often seems to be interrupted, in comparison to more focused, uninterrupted care rendered to older residents. Mike explains his morning toileting routine:

Mike: *They come in and wake me
up, then they carry me to the
toilet, then they leave, and I
sit there until they get back.*

S. English: *How long do you sit there?*

Mike: *As long as it takes.*

S. English: *How long is that?*

Mike: *Sometimes, a while. I don't
know... twenty, thirty minutes?*

Longer, sometimes.

This corresponds to Edgar's frustration about CNAs being unwilling to adequately clean him, following toileting. "I don't know why they treat my dick like poison. I can't do anything with it, anyway." Lesser treatment of non-traditionally aged residents is not unique to CNAs. Nurses, doctors, and Activity professionals commonly walk past younger residents, with younger residents often initiating interactions, if there are interactions, at all. Social Workers, too, appear to spend less time *on the floor* with younger residents; however, all four Resident Participants report positive relationships with Social Workers and frequently visit the offices of Social Workers, though not always the Social Worker assigned to their case. One of the Social Workers, Maria, often assists Leonard, who once lived on her unit, sharing: "Leonard still comes by whenever he needs me to cancel a subscription or something." Indeed, Leonard called me from Maria's office one day, talking to me over the speakerphone to request a time change for one of our interviews.

Overall, time spent between non-traditionally aged residents and Care staff seem perfunctory and task-oriented, when compared to interactions between residents and Support staff. This informed an additional theme, below.

Theme # 8: Non-Traditionally Aged Residents Describe Seeking Out Social Connections to Personalize the Way They Are Perceived and Improve the Delivery of Services

The longest and most personally directed interactions between staff and non-traditionally aged residents occur with Support staff, whose work tasks are not directed by formal plans of care. Dietary, Housekeeping, Laundry, and Maintenance staff

were observed consistently engaging with younger residents in uninterrupted ways. Some of my notes from field observations read: Younger resident talking to Maintenance staff; Dietary staff bringing orange soda to younger resident; and other notations of interactions between Support staff and non-traditionally aged residents. Though some of these interactions between Support staff and Resident Participants are task-oriented, such as mopping the floor in the younger resident's room or delivering a breakfast tray, many interactions between Support staff and younger residents appear voluntary and more personal, with this group of staff members frequently performing special tasks, even without being requested.

For example: I observed interactions between Support staff and younger residents while at the nurses' stations and while conducting interviews. One woman who works in the Laundry Department, Hildy, interrupted an interview to present Walter with a crisply ironed shirt to wear as he gives the Sunday blessing. On another occasion, I found two maintenance employees sharing a joke with Leonard, as they hooked up his Roku.

I asked a few Support staff about their perspectives of younger residents. Hildy, who is relatively the same age as the Resident Participants offers that she "could not imagine" being a resident of a nursing home, especially at so young an age:

It doesn't take any time at all; in fact, I like them. You know, I went to school with a couple of them. Yeah, I used to ride the bus with Steve (a younger resident who was not selected for this study). They're my

*age. I can't imagine. I just can't
imagine.*

In contrast to their comments regarding Care staff, all Resident Participants speak fondly of Support staff. Walter notes Support staff as “helpful” and “kind.” Edgar and Leonard describe Support staff as “special.” Leonard speaks of his dependency on Support staff, noting: “I need them for lots of things. They fix my T.V., my (wheelchair) battery.” For non-traditional residents, persons who work as Support staff, whose work is not directed by plans of care or medical records, are perceived as treating them more individually than Care staff. This was evidenced by Support staff greeting them by name, providing non-interrupted interactions, and personalizing exchanges. Resident Participants note that they know who to approach, as this exchange with Edgar illustrates:

Edgar: *I know who to ask if I need
something.*

S. English: *You do?*

Edgar: *Yeah. It's not hard, you just
look for the uniform. If they
are wearing a uniform, they
are usually OK.*

S. English: *But, the CNAs wear
uniforms.*

Edgar: *Not the same, not the same. A
real uniform has got buttons.
If somebody's wearing*

buttons, you know they're

OK.

Theme #9: Care is Standardized, Not Personalized

Over the course of this research, I examined several documents of care, including resident face sheets, psycho-social assessments, PASSR documentation, BIMS assessments, and Multiple Disciplinary Assessments. These documents are considered a part of each resident's EMR and inform individual plans of care for nursing home residents. Multiple disciplinary care teams include representatives from the departments of Activities, Dietary/Nutrition, Nursing, and Social Work. These teams review the plans of care for permanently admitted residents quarterly, or upon a significant change of condition. Plans of care outline goals and objectives for each resident and direct how services are delivered. Though plans of care are intended to be person-centered, goals appear general and broadly judgmental, rather than specifically targeted to a particular person. For example, several plans of care noted this goal: "Resident will continue to display appropriate behavior during group activities." A memo I wrote after reviewing several documents read: "What does this mean? What does 'appropriate' mean?"

Findings observed from documents of care illustrate the lack of person-centered care. Person-centered care is a declared goal of the Administrative staff. As the Director of Social Services explains: "We make sure to personalize all plans of care to reflect each unique person." Despite this statement, needs were standardized on the EMR, which serves as the formal document of care. Activities, bowel movements, food intake, medication regimes, and personal care are documented by Care staff who sit the C.O.W., open up each resident's EMR, and check a series of boxes by clicking a mouse.

Specific concerns are shared through less formal documents and material culture, such as the “Communication Log,” that details daily concerns and changes of condition, and the “Behavior Book,” which identifies residents with a history of verbal or physical behavior, refusal of services, disruptive behaviors, threats of harm to others, or symptoms of psychosis. Additionally, residents noted as having specific behavior concerns, such as elopement or physical aggression toward staff are sometimes identified with stickers, placed on the spines of resident charts or on nameplates, located outside of resident rooms. Residents at risk for elopement are sometimes identified by a giraffe sticker; persons who have a history of refusing personal care are sometimes identified by a volcano sticker. Though prevalent on some units, sticker use is inconsistent across units. May, the Unit Secretary told me:

Yeah, those are from one of the nurses. She thinks it helps identify problems. She worked downstairs for a while and put those stickers on almost every door. The day after she went to another unit, I tore them all off.

The Sticker Nurse has worked at Golden Acres for over 20 years, making her way through most of the nursing units. When, I worked at Golden Acres, she floated between different shifts and areas. Shortly after I started working at the nursing home, I asked about the stickers. May, who then worked on one of “my” units, explained what they meant. I recall May saying: “one of the nurses put them out” and had placed little stickers

throughout the building, as she moved from unit to unit. Over time, I forgot about these stickers, but when I returned to Golden Acres as a researcher, I found the sticker use very inconsistent, prevalent on some units, but absent on others. Care staff generally ignored them. May's unit, a locked unit that provided care for persons displaying the most "serious behavior issues," including a history of harm to themselves or others, no stickers, either on charts or doors. "We know who lives with us," said May.

Identification of concerns, either through the "Behavior Book" or stickers, do not always correspond to the current assessment or plans of care but are an historical legacy of admitting diagnoses. For example: all Resident Participants are identified as concerns in the "Behavior Book," despite having no history of aggression during the past two assessment cycles. Edgar's entry in the Behavior Book, identifies him as "antisocial," noting antisocial behaviors that are to be dated, detailed, and documented, despite the initial date of concern being several years old.

Concerns about Mike and Walter are noted in the Behavior Books of their respective units, with no entries. Leonard's unit does not have a Behavior Book available, nor do nurses utilize stickers to identify behavioral concerns. I opened every available Behavior Book while observing the units. No entry was less than five years old. Over the course of my observations, I did not notice anyone accessing a Behavior Book to document concerns or read the recommended responses, including de-escalation techniques for incidents of aggression or other behaviors that were included with every notification. Neither did I observe anyone making an entry regarding behavioral concerns through a formal incident report or the EMR. Behavioral concerns were, instead, reported to the floor nurse who dispenses PRN psychotropic medication(s), prescribed in the event

of the resident “acting out.” “We just handle it,” shrugs Norma, one of the RNs.

The CNAs do not appear to access resident-specific information and, instead, rely on what Tyrone calls his “gut” to decide what the residents needed. Care that extends beyond scheduled tasks, similar to some medication, is dispensed PRN, as well. Larry, one of the CNAs in the Focus Group, shares:

Larry: *So, the days go pretty quick,
there’s a lot to do.*

S. English: *What’s your typical day like?*

Larry: *Well, I come in and check
what’s going on, you know,
in the Communication Log, to
see if anything special is
going on.*

S. English: *What would be special?*

Larry: *Like somebody’s birthday or
somebody having a bad
day... unusual things... then,
I start with the showers. That
takes a while. Then, I get
ready for dinner, help the
feeders, clean up. Then, I
help the ones that want to go
to bed, to bed.*

S. English *That sounds like a lot.*

Larry: *Yeah. There's not much time to do anything else. They tell you all this stuff you could do, but about half of the day is doing what needs to be done and the other half is documenting that you did it. I sit at the C.O.W. for at least an hour, just clicking.*

S. English: *Clicking?*

Larry: *Yeah. I gotta click all those boxes. Just sit there with the mouse and click, click. If you miss a click, you can get in trouble, even if you did the thing you're clicking about.*

S. English: *What else do you do during the day?*

Larry: *Well, I'm usually the only guy working, so if there's a problem they come and get me, like if somebody is acting*

up or something.

S. English: *How do you know what to do,
when people act up?*

Larry: *You just gotta go with it. You
figure it out.*

Despite daily notes in Communication Logs, recommendations in Behavior Books, and plans of care that were updated at least every 90 days, the Resident Participants did not receive personalized care. Rather, Care staff provided for residents according to check lists and standardized forms. The disconnect between documents intended to direct care and staff behaviors manifested in Care staff reacting to the personal needs of residents, rather than responding to them.

In the LTC environment, inconsistencies between formal documents, such as Electronic Medical Records and plans of care, and informal documents, such as Behavior Books and Communication Logs, seem to echo inconsistencies between what is said and what is done. Comments from nurses about “knowing what to do” are similar to the way Resident Participants identify those who help from those who do not, which informs the final theme of this research.

Theme # 10 Social Connections Appear Preferred over Formal Channels to Leverage Improvement of Delivery of Services.

The Administration of Golden Acres emphasizes Residents’ Rights. A copy of the Residents’ Rights policy is posted at every timeclock and nurses’ station. Residents are provided with a personal copy upon admission and all staff are required to participate in an annual Resident Rights in-service program. Contact information for the regional office

of the Ombudsman is posted on every floor.

Transparency about care is encouraged and all residents, family members, and responsible parties are invited to the quarterly Care Plan meetings. Despite this open invitation, none of the Resident Participants attended these meetings and none of them had elected to do so.

Leonard, who has lived at the nursing home for the whole of his adult life, has only attended two Care Plan meetings in 44 years of residency. When asked why he doesn't attend Care Plan meetings, Leonard leans forward, saying:

*I've got better things to do than
waste my time with that mess. They
are going to write down whatever
they want anyway. Those meetings
are just a bunch of paperwork. Just a
bunch of paperwork.*

Edgar, too, recalls his past participation in Care Plan meetings as less helpful than direct connections for getting him the things he needed or wanted.

Edgar: *So, I go to that
meeting because I
was invited, you
know? All I wanted
was hot coffee, you
know like the coffee is
always cold. So, when*

*I bring it up, they say
that's not what the
meeting is about. Why
have a meeting then?
Anyway, I told this
one nurse about it,
and now I get coffee
straight from the pot.
Done.*

S. English: *So, why do you think
that worked?*

Edgar: *Oh, you know, she
likes coffee, I like
coffee. She likes me. I
get coffee.*

While the delivery of task-oriented care - assistance with ADLs, behavioral goals and objectives, wellness outcomes – seems to follow formalized documents, the *manner* of delivery is influenced by the way staff perceive the resident and the type of staff who are delivering the services. The Resident Participants use social connections to personalize the way they are perceived, which they believe improves the delivery of services, leveraging change through informal interpersonal channels.

Perceptions of the residential experience are influenced by interpersonal experiences. Findings from this embedded case study indicate that staff perceptions about

non-traditionally aged residents living in the LTC setting are influenced by connections residents have to, and with, staff. Participants in each group – Resident Participants, CNAs, Social Workers – indicate the importance of relationships, with participants describing the importance of personal connections, including the power of these connections to influence the way they are “seen” by staff.

Non-traditionally aged residents employ strategies and intentional actions to establish connections to Support staff and those they perceive as having power. Though non-traditionally aged residents are observed to experience fewer interpersonal interactions with staff than older residents, Resident Participants who intentionally made efforts to connect to staff – especially Support staff – are perceived positively. This is true when interactions are not task-directed, especially in Support staff-to-Resident Participant interactions, including: using time off to run personal errands for younger residents, ironing younger residents’ clothes, sharing videos with younger residents, activating younger residents’ cell phones and other devices, braiding younger residents’ hair, delivering *coffee from the pot*, and sharing personal photos, books, and magazines. It surprised me that the positive connections between LTC staff and non-traditionally aged residents did not seem to influence formal documents of care, including face sheets, psychosocial assessments, and multiple disciplinary plans of care, which seem, instead, to echo concerns noted on initial assessments completed shortly after the younger resident’s admission to the nursing home. These formal documents of care often focus on resident deficits and report negative perceptions of non-traditionally aged residents, often describing younger residents in the EMR as having a history of being “demanding” or “non-compliant,” regardless of the presence or absence of these behaviors. This is

Edgar: *Well, my friends are
people I hang with.
My friendlies are
people I need stuff
from. If we are
friendlies, then I know
they see me for me. I
know I can get what I
need when I need it. I
know they don't think
I am some crazy guy,
like the others. I'm
me. I want them to see
me for me, ya get me?*

S. English: *So, are you friendlies
with everyone?*

Edgar: *No! I just figure out
who I need, and I get
friendly with them.*

Mike was less successful: *"I'm not friendly with anyone. I used to try, but they
pretty much see me like everyone else, so I just stay to myself."*

Walter also saw friends different from "friendlies." Explaining that the people he
considered friends lived outside of the nursing home, but the persons he was friendly

with worked at the nursing home. For Walter, being perceived as an individual was a way for him to be seen “apart from the big lump of everyone else” and social connections were investments for better delivery of services in the future. Walter summed it up as an exchange:

Walter: *I'm willing to get involved, I'm willing to listen to them and interact in their lives and they're willing to interact and get into my life. You have to do that in order to survive in here or anywhere else. Yeah. Be willing to give. You have to be willing to, um, not only take, you have to be willing to give.*

S. English: *So, what do you give to them?*

Walter: *This thing, here*
taps head

Oh, and this

thing, here

taps heart

Sometimes.

Summary

This embedded case study describes the perspectives of non-traditionally aged residents living in LTC settings and reveals that perspectives of non-traditionally aged residents are influenced by life experiences, values, and social contexts. Analysis was conducted using multiple points of data associated with this research and reveals how non-traditionally aged residents perceive the way they are perceived by others, respond to these perceptions, and employ intentional actions to offset negative perceptions and improve delivery of services. Though the described intensity of these actions appeared to vary among the individual Resident Participants, each Resident Participant described strategic actions as a means of leveraging services and things

CHAPTER 5

DISCUSSION

If you are aware that somebody has a favorable impression of you... you see your image there in a certain favorable condition and you appropriate that... If you grasp these facts and see what they involve, you will of course see the importance of the social self.

- Charles Horton Cooley

There is little existing literature about non-traditionally aged residents of LTC, and the literature that does exist, tends to focus on the appropriateness of placement for younger persons in these settings. Existing research discusses the need for alternate placement options but fails to account the housing limitations for younger persons who face little to no choice regarding placement. The dearth of housing options, as well as the multiple disadvantages faced by Resident Participants, appears to influence the way they perceive themselves, the way they are perceived by others, and the way they perceive they are perceived.

Clustering of disadvantage complicates and limits options for non-traditionally aged residents, who often languish in care for decades, due to dependency on others to meet physical needs (physical disability); the reliance on public funding to cover costs of care (low SES); the absence of social support from advocates outside of the LTC setting (estrangement); and assessments documenting the potential of risk to themselves or others (severe mental illness). The Resident Participants of this study all experience

multiple disadvantages of disability, low SES; social estrangement, and mental illness; however, they demonstrate skills and strategies that counter negative perceptions staff may have of them, leveraging social connections to garner more personalized and positive care.

In this chapter, I synthesize findings discussed in Chapter 4 and how they correspond to existing literature. I also discuss how these findings expand existing literature; how this research may contribute to the current literature regarding Long Term Care; implications for policy and practice; strengths and limitations of the study; and recommendations for additional research.

Findings

The LTC setting is the primary influence on this study. It bounds the environment and contributes to the functional identity of the space, influencing day-to-day activities, including the perceptions and behaviors of persons who live and work within this setting.

The total institution of the LTC setting that bounds this study also frames the perceptions of both staff and residents, which influence, and are influenced by, formal and informal communications of care (Goffman, 1961). Though all perceptions and behaviors are influenced by the social settings where persons live and operate, the restricted nature of the total institution concentrates the influence of space and place for persons who live and work within. Goffman (1961) and Schwartz (1971) noted that the perceptions and behaviors in total institutions are indigenous responses, reflecting the influence of the environment. The perceptions and behaviors of persons that live and work at Golden Acres appear to be reciprocal reflections of the social setting.

Within the space of Golden Acres, non-traditionally aged residents demonstrate

the repeated and intentional engagement of actions to influence the way they are perceived by persons of perceived power that extends beyond care-related tasks. These actions appear informed by the intertwined influence of three elements: place, control, and relationship (Figure 5.2). Triangulation of the data reveals that these three elements are present across all units of analysis, with place (where an individual fits within the social environment), and control (level of agency and access an individual has within the social environment) intertwined with the relationships the individual experiences, within the bounded space of Golden Acres.

Though Resident Participants who report less engagement appear to have less benefit regarding improved delivery of services (i.e., Mike), all Resident Participants noted intentional engagement as a means to improve access to services and things. I coded and analyzed intentional actions undertaken across the units of analysis, which arise from the nexus of these three elements.

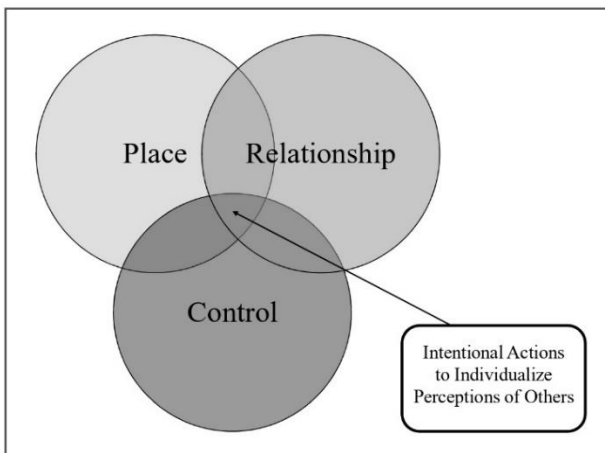


Figure 5.2. Factors influencing actions and behaviors of non-traditionally aged residents in the LTC setting.

Place

Where one is situated within a social space – one’s *place* – influences perceptions and behaviors. In this study, place and the understanding of the place of others, appears to inform the decisions and actions of persons who live and work within the LTC environment.

Resident Participants seem to believe that their *place* within the nursing home determines their social role and they make efforts to differentiate themselves from the larger population. The Resident Participants of this study describe perceiving themselves as unique, expressing frustration at being “lumped together” with other residents, though they also “lump” residents together, collectively describing them as “crazy,” “confused,” or “frail.” The Resident Participants describe action as necessary to differentiate themselves from others who live in the nursing home, explaining this as a way to get more individualized attention and better care.

The Resident Participants describe admissions to LTC as “fate,” with all of them claiming a social role as an advocate, responsible for “looking out for those old people.” Walter explains: “God put me here. Maybe God wanted me to look out for some of these people who can’t look out for themselves.” Acts of advocacy, for themselves or others, appear to provide the Resident Participants with meaningful social roles. Walter notes that the Activity Director counts on his help. Edgar refers to the place he sits outside the beauty shop as “my workplace” and he recalls his successful discount negotiation at the staff dining room with pride. Though negotiations for themselves or others are not always successful, the Resident Participants continue to perceive these efforts, and their advocate roles, as important. Leonard continually lobbies for a name-tag without success, telling

me he has “worked here longer than almost anyone else.”

These helping roles are not described as completely altruistic and are noted as being undertaken to also “work the system,” as Leonard says. I like to “see what I can get” agrees Edgar. Even Mike, whose moves are more passive than other Resident Participants, makes efforts at being known:

*They know I complain, so they know
I know what’s going on. If they know
that, then they don’t mess with me...I
am Mike. I want to be called Mike. I
want to be treated like Mike, not just
some guy who lives at a nursing
home.*

Despite the way the Resident Participants define their place in the nursing home, they express frustration at being perceived in the same way as other residents, making efforts to be personally known.

Perceptions of place also appear to extend to the Resident Participants’ perceptions of workers, with Resident Participants evaluating the place of the staff, according to how much power the staff member has to make decisions, without direct guidance from supervisors or checklists. Staff members who assess or assist with ADLs are considered care workers, who perform work according to instructions from others. Care staff, such as CNAs, are often not approached, as Resident Participants seems to believe these staff members fill subservient roles within the institution. “They can’t do nothing without being told to do it. If it isn’t on the computer, it doesn’t get done. It’s a waste of my time

to ask them to do anything,” explains Walter. “They do what they’re told,” says Mike. “Nothing more, nothing less.” Administrative and Support staff are defined by Resident Participants as more independent and perceived as potentially more helpful, influential, and more likely to facilitate better care. Walter explains:

You have to watch and you have to listen. You have to figure out who really makes the decisions. Lots of times, it isn’t who you think. Like, if I want something to eat that isn’t on the menu, I ask Mack. He’s not in charge of the kitchen, but he delivers the trays. If I ask him, I get it. If I ask the nurse, like I am supposed to, nothing gets done. I don’t even need to ask him anymore. He just goes ahead and brings me what I like.

Place appears to influence the perceptions and behaviors of staff, as well. Staff members’ sense of place seems to determine the way they believe they are perceived by work peers. This is especially evident among newer workers who defer to those who have been employed for a longer period of time.

While the sense of place seems to limit interactions between Care staff and residents, it also encourages interactions between Support staff and Resident Participants. For example: Mack, who’s job description notes his role as a Food Services Assistant,

explains that his role is “keeping people happy” and Lonnie, a Maintenance Worker, states that his job is to help out “anyone who needs it.”

Control

Goffman (1961) noted that total institutions restrict personal will and control. This lack of control was also noted by Wolff and di-Shalit (2007), who asserted that persons experiencing multiple disadvantages tend to experience less control over their environment. Hector (2016) suggested that a negative relationship exists between disadvantage and autonomy, with more aspects of disadvantage associated with less personal choice. I coded and analyzed tensions between institutional control and resident autonomy.

Resident autonomy appears restricted in many ways. Resident Participants note frustration at being awoken early, having to eat when someone serves them, having to eat what is served, being approached by staff to take showers in the middle of the day rather than in the morning or evening, and being put to bed at an early hour. For example: Walter, lives with Congestive Heart Failure, and is relegated to what he calls “low salt, low fat, low taste” meals. Edgar’s freedom of ambulation is limited because of his lack of peripheral vision, which is noted on an assessment as “too risky to operate an electric wheelchair.” Leonard shares that his back often hurts during the late afternoon, but “the doctor says I have to stay up at least 12 hours a day.” Mike’s assessment notes difficulty with “urgency incontinence” and he is placed in Depends because the “staff can’t always get to me in time.” Residents express frustration by the lack of food choices and activities “that are just for old people.” Things enjoyed prior to admittance are described as no longer possible. “I can’t even smoke. This place is smoke-free,” says Edgar. ‘I can’t

remember the last time I had a beer,” Mike shares.

Additionally, despite written policies supporting resident privacy and *the right to engage in relationships*, Resident Participants note that restrictions extend to sexual activity, which they describe as non-existent. “Everything still works, you know,” states Mike, “but, it’s like people forget that part of you once you go through those doors.” Leonard often enrolls in trial subscriptions to erotic movie channels and magazines, making sure to visit the Social Worker, Maria, who helps him cancel his subscriptions before his account is charged. “I have a special email for my subscriptions. My username is Dr. Love. My old Social Worker (Maria) helps me sign up (and cancel). I don’t ask my new one. She doesn’t know me like my old Social Worker does.”

Findings reveal that Resident Participants appear to leverage social connections in an effort to control their narrow environment. Using social connections as links to services offers a measure of control within the total institution. Though Goffman (1961) noted persons living in institutions as dispossessed of role and control, the active assessment and intentional actions of these younger residents illustrate how persons who experience multiple restrictions may utilize social connections to expand the narrowness of life in the LTC setting.

Control is also mentioned by Care staff, who describe being overburdened by tasks related to documentation about the delivery of care and assistance with ADLs. “I have a lot to do,” explains Cynthia, a CNA. “Every day, they keep adding more and more on me. I don’t have time to do anything extra. I just do what I’m told.” Taj, another CNA agreed, “We have these lists and these checks we have to make on the C.O.W. If we don’t check it, it didn’t happen. There’s no time for anything else.”

While Care staff describe that much of their work-day involving documenting what they do, Support staff, such as Laundry workers or Maintenance staff, describe the purpose of their job as “being helpful.” Indeed, most of the observed Support staff interactions with non-traditionally aged residents involve the performance of “favors” off the clock or in addition to work expectations. “I gotta go to the store anyway,” explains Pete, a maintenance worker. “It’s no big deal to pick up a cord for Leonard when I’m out. He might never get it if I don’t do it.”

My observations on the living units revealed longer and more prevalent interactions between younger residents and Support staff than between younger residents and Care staff. Interactions between younger residents and support Staff also appeared positive, as evidenced by laughing and smiling. A review of my field notes documents two Maintenance staff in Leonard’s room when I arrived for our second interview, explaining: “We’re just hooking up Leonard’s new Fire Stick, won’t be a minute.” Field notes also document interruptions of interviews with Walter: once, when Hildy brought the freshly ironed shirt for him to wear to Sunday School and another time, when a Dietary Aide brought Walter a chocolate brownie, looking at me, smiling, holding a finger to his lips, and vocalizing: “Shhhh.” Notes also document Support staff leaning against walls, talking to Resident Participants and, on one occasion, holding the elevator door open as Edgar waited to go to the lower floor, and sharing a joke, while the elevator alarm sounded – bing. Many observed conversations between Support staff and non-traditionally aged residents were observed in the breezeway, as Dietary staff moved large metal carts from the kitchen to the living units or other Support Workers moved between the Administrative side of Golden Acres and the residential units.

Summary

The Resident Participants consistently describe and demonstrate actions to influence the perception of others, as well as improve the delivery of services. For example, if residents perceive staff as incompetent, they describe seeking out someone they believe to be more able to make good decisions. If Resident Participants perceive staff as treating them unfairly, they assess the situation, determine who might be influential, and approach the more powerfully perceived person, to secure treatment that is fairer. If the Resident Participants perceive they are being “lumped” together with others, they take active steps to make themselves known in social situations, asking staff about children, eating in the staff dining room, or as Edgar puts it: “just getting my face out there.”

In the closed space of the LTC setting, non-traditionally aged residents engage in active evaluation of place, control, and relationships over the environment, appearing to use this information to inform actions that influence how they perceive and are perceived, and the way they treat and are treated by others. Though Golden Acres meets Goffman’s characteristics of a total institution and Resident Participants meet Wolff and de-Shalit’s descriptions of persons living with clustered disadvantage, Resident Participants engage a secondary adjustment to the environment, beyond those described by Goffman (1961), where non-traditionally aged residents do not seem to submit to the total institution but rather, shift within it.

The Functions of Perceptions Through the Looking Glass

Perceptions are functions of the social world; the social world is a function of perceptions (Cooley, n.d.). Cooley (1902) argued that all truth is perception and

reality is a process of subjective mirroring, describing social facts that are tied to social contexts. Cooley (1902) described all human interaction as a connected web of communication, with social reality influenced by perceptions and behaviors. As Reiss (1968) noted: “it is not what people are but what we think they are that determines our reaction” (p. 14). Almost sixty years after Goffman, this study aligns with Cooley’s Theory of the Looking Glass Self, as demonstrated by the way non-traditionally aged residents are perceived in the LTC setting, the way non-traditionally aged residents perceive themselves, and the way they perceived they are perceived. Yet, findings demonstrate something beyond Cooley – the Resident Participant’s belief in the influence of their actions upon the perceptions of staff members that they feel will assist them in obtaining access to services.

Intentional Actions and Behaviors Influence the Process of Perceptions

Findings suggest a reciprocal relationship between perceptions and behaviors, both of the staff and the Resident Participants. Resident Participants appear to accurately perceive the way they are perceived by LTC staff and engage in social connections with persons they perceive as useful for improving the delivery of services, within the LTC environment.

Life experiences, values, and social contexts contribute to bias that is mediated by the social connections and social culture of the setting in which connections occur (Banaji & Greenwald, 2007; Pfister et al., 2015). My observations revealed bias reflected in the material culture – documents of care, post-it notes on Communication Logs and C.O.W.s, and stickers on doors - of Golden Acres. Findings also reveal that Resident Participants are aware of this bias and describe attempts to moderate it through

intentional and strategic actions and behaviors, which they describe as personalizing the way they are perceived within the environment, influencing perceptions of LTC staff, and enhancing the delivery of services. Figure 5 depicts this reciprocal process evidenced at Golden Acres.

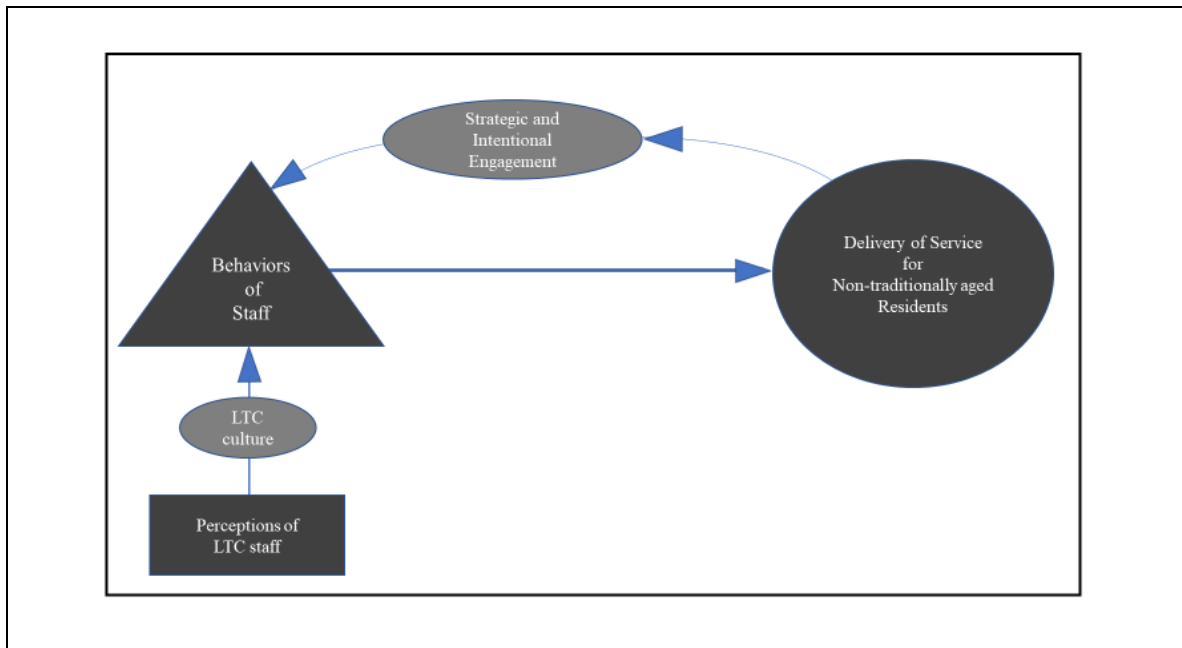


Figure 5.3. Conceptual model of the perception feedback loop of perceptions and behaviors.

Figure 5.3 illustrates a continuous feedback loop of perceptions and behaviors, showing that they are not *set*, but dynamic and influenced by intentional action to create social connections to others. The **Perceptions of LTC staff** appear influenced by the individual APEs staff have as they first enter the setting and are, for this study, the initial point of perception for staff, who are influenced by attitudes (i.e., all residents are the same), perceptions (i.e., younger residents are distracting, demanding, or dangerous in the LTC setting), and values (i.e., younger residents are living in the LTC setting as a result of bad choices and risky behaviors).

In this study, the **Behaviors of Staff** toward non-traditionally aged persons seem to influence the **Delivery of Service for Non-traditionally Aged Residents**, including the failure of staff to address them by name or passing in the hall without acknowledgement. These behaviors appear influenced by the social culture of Golden Acres, where existing employees set the tone for new employees as they learn how to deliver services to younger residents, their reactions to younger residents, and their behaviors toward younger residents.

The time-constrained nature of interactions also influences treatments, reactions, and behaviors and appears to inform the *material culture* created and maintained within this setting. This material culture is expressed through formal and informal artifacts, including Behavior Books, documents of care, sticker use, and staff-to-staff communications via post-it notes and Communication Log entries.

Resident Participants describe awareness of how they are perceived by staff and attempt to offset negative behaviors through intentional actions (i.e., socially inserting themselves into conversations, dining with staff), which positively influences the perceptions of – and behaviors toward – them.

I observed Resident Participants who reported these strategic engagements of social connection with staff as receiving more personalized care and appearing to have positive social interactions with staff. These social connections appear to further influence the behavior of staff, including the use of formal and informal artifacts, documentation in Behavior Books, writing of assessment notes, the presence or absence of sticker use, and more positively, the expressed opinions of staff regarding particular residents.



Figure 5.4. Poor House Road (English, 2019)

Relationship

Positive relationships are correlated to better health and wellness; however, the Resident Participants all express limited social networks. All Resident Participants mentioned social estrangement from “outside” friends and family, but they do not view social connections with staff as substitutes for social ties to persons outside the LTC setting. Perlman (1979) described relationship as a conscious negotiation between persons and argued that negotiations are primary ways that individuals interpret meaning in their world and the foundation of all social connection that “grows out of some interchange” within a social context (p. 141).

The persons who live and work in the LTC setting are in close contact and negotiate several times throughout the day. Findings reflect that Resident Participants use social connections as links to services within the total institution, approaching those whom they perceive as likely to help and work to establish relationships with them.

Walter shares: “I ask them about their kids, you know. When you start asking about kids, people automatically start talking to you.” Edgar used a similar strategy, usually approaching Support staff.

Edgar: *I start talking to them, they start talking to me. Once they know me, I know I can ask them if I need anything special.*

S. English: *Like what?*

Edgar: *You know, like if I need a magazine or a candy bar or something. If I want a Coke.*

S. English: *So, you ask them to get you candy and Coke?*

Edgar: *Yeah, but other things too.*

S. English: *Such as?*

Edgar: *Well, it's like this... the other day, my back hurt and I wanted to go to bed. They make me stay up all day until they have two people to lift me up on this thing (the mechanical sling), so I told*

*Lon. Next thing you know,
they were coming to put me
to bed.*

S. English: *You didn't tell the nurse?*

Edgar: *No. She's too busy. I let Lon
tell her. It got done.*

Though Goffman (1961) noted persons living in institutions as dispossessed of role and control, the active assessment and intentional actions of these younger residents appear to illustrate how persons who experience multiple limitations utilize social connections to expand the narrowness of life in the LTC setting. As Walter notes: "If I need something, I know what to do. I know who to ask. They hook me up."

The Resident Participants do not describe relationships with staff as friendships. Instead, these relationships serve as a means to: 1.) secure the things they want and 2.) to differentiate the Resident Participant from the "lump" of other residents, with social connections viewed as a means to control their limited environment. When I ask Edgar if he considered some of the staff his friends, he adjusts himself in his wheelchair, leans forward, and says: "No Girl, they ain't my friends. My friends would be people like me. They ain't my friends. They just a way to get what I need. Friendly? Yeah...but ain't friends."

The functional importance of social connections established between the Resident Participants and staff, particularly Support staff, are expressed by Leonard, who describes his relationship with the Maintenance staff:

Leonard: *My life would be a lot different without those guys. They hook up the Roku, fix the cable. Nobody else does stuff like that. Nobody else has the time.*

S. English: *Do you consider the Maintenance guys your friends?*

Leonard: *Mmmm, no. I mean, not really. You know, it's like they do things because of me, because they know me, but they don't do it because they are my friend or anything.*

It is important to note that none of the Resident Participants use formal procedures to lodge concerns or requests. They do not participate in quarterly assessment meetings, they do not participate in the Resident Council, and they do not lodge complaints through incident reports. Rather, they approach staff they assess as helpful or

powerful, such as the Administrative Staff like Unit Secretaries, long-standing staff members they perceive as having clout, support staff who possess particular skills, and Social Workers they deem effective. I coded and analyzed Resident Participants' perceptions regarding staff helpfulness. Staff that were perceived as guided by taskings were seen as too busy to help. Staff that were perceived as "green," were seen as lacking power to make decisions. These staff members were described by Resident Participants as "dumb" or "bad" or "nasty." Staff that were perceived as helpful - whether through observation of them or personal experience with them – were described as "smart" or "good" or "useful." Social connections appeared made and maintained with those who were smart or good or useful, regardless of where the workers were assigned or what job description the workers had. This is illustrated in the way Edgar takes concerns to the Director of Nursing or one of the Social Workers who works on another unit, instead of the Social Worker assigned to his case, stating: "My Social Worker, she's nice, but she's green, you know? She's new. Who's gonna listen to her? If I need something done, I go to someone who can get it done."

Contributions to Existing Literature

Current literature primarily reflects safety concerns regarding the incorporation of younger persons into LTC settings; however, most documented concerns do not accurately reflect the behaviors of non-traditionally aged residents. I argue this inaccuracy contributes and reinforces bias that influences the way younger residents are perceived by LTC Care staff.

Several studies discuss safety concerns about younger residents in the nursing home environment, noting concerns about violence directed from younger residents to

older residents and staff. Findings from this study demonstrate that these concerns are not pervasive. Indeed, the examination of the EMRs shows that none of the Resident Participants have a documented history of violence at the nursing home, despite psychosocial assessments and Behavior Books noting Resident Participants as having a “history of physical violence.” Nursing staff state that most altercations between younger residents and staff are short-lived arguments about showers and food. Additionally, data from Focus Groups in this study reveal that staff do not consider younger residents dangerous or violent, as in this exchange:

Tyrone: *Anyone can be violent, I guess, with enough stress. These guys aren't any more violent than anyone else who lives here. The only time I see them get in someone's face, is when someone gets in theirs.*

Taj: *Yeah, that's true. If you listen to them, everything's OK. I mean, I get frustrated if nobody listens to me.*

Larry: *I have been here a long time and I never saw any of the younger ones be violent. They complain a lot, but that's it.*

Cynthia, who has worked as a CNA in the nursing home for over twenty years, describes arguments between older and younger residents:

But, it's usually because the younger person wants to get by, and the older person is blocking the hall. If the older one can't hear, it looks like they are ignoring the younger one. Then, the younger one will yell. It can get kind of noisy, but it's no big deal. We just move the older person and it's solved. I've only heard of one incident in twenty years, and that got blown way out of proportion.

This study moves beyond the description of non-traditionally aged residents as being problematic in the LTC environment. It demonstrates the connection between perception and behavior, among residents and staff at Golden Acres, informing what people *think* and what people *do*, through “natural social observations, capable of being recorded and leading to understanding and prediction through an equally natural process of imaginative inference” regarding similar individuals (Cooley, n.d.). The findings reveal the way non-traditionally aged residents connect thinking and doing by evaluating perceptions of staff and incorporating intentional behaviors to socially connect with workers who are perceived to be helpful. This inference of helpfulness is informed by

how Resident Participants experience their place within Golden Acres and increases not just the delivery of services, but also Resident Participants' beingness within the community of Golden Acres. How Edgar and Leonard and Mike and Walter perceive the way they are perceived by others, informs the way they *are* within the community, and the way they are *of* the community.

Implications for Policy

In describing the residential experience of non-traditionally aged persons living at Golden Acres, the need for changes in policy, at organizational, state, and federal levels, become abundantly clear. The Resident Participants describe living in the nursing home because they have no other choice readily available. This finding suggests that current policies regarding alternatives for housing should be addressed. Community homes are often unable to accommodate persons living with multiple disabilities (Connery, 2016), The community-based care homes which do, will often not consider placement for persons with a history of severe or persistent mental illness (Gabrielian, Young, Greenberg, & Bromley, 2018). Community homes that target care for persons living with mental illness, are often unable to care for those who require intensive assistance with ADLs (Hunter, Harvey, Briscoe, & Cefalu, 2017). Assisted Living Facilities and retirement homes often have expectations for residents to independently evacuate the building in the case of emergency (Assistant Secretary of Planning and Evaluation, Department of Health and Human Services, 2015). Further, Berridge (2018) reported that community-based homes are private pay and fail to accept Medicaid waivers to cover the cost of housing, severely limiting options for younger persons who are permanently disabled, with little to no income, and a history of mental illness. Well-off, well-behaved

older persons have an abundance of options that are unavailable to persons who are poor, sick, and young.

Future policy consideration might involve staff-training. Findings from the focus groups demonstrate that staff feel the needs of all residents are similar; however, the needs of persons who are young adults and middle adults vary considerably from those who are in later developmental stages. Staff training could provide better understanding of the unique stressors faced by younger residents, including estrangement from family and how admission thwarts aspirations for careers and relationships of persons who may languish in nursing home care for decades. Assigning care staff to particular residents may help build relationships that expand social connections, increasing social interactions between care-staff and non-traditionally aged residents, elevating the roles of workers beyond the completion and documentation of tasks that are measured by billable units of time.

Implications for Practice

This research has implications for Social Work practice, especially regarding interpersonal relationships for non-traditionally aged residents in the LTC setting. Social Workers who work in LTC are tasked with evaluating residents and setting psychosocial goals and objectives. “Establishing meaningful relationships” is noted as a current goal for three of the four Resident Participants, yet no specific objectives note ways for these non-traditionally aged persons to establish such relationships. Resident Participants who appear to positively negotiate social connections did not identify these connections as particularly meaningful; rather, social connections were useful ways to manage institutional limitations and improve the delivery of services. Staff training incorporating

knowing into tasks may address the *blindspots* of bias staff express regarding non-traditionally aged residents and enhance the living and working experiences for persons within the LTC setting. Requiring Care staff to know a bit about the personal histories of residents with whom they work would echo the personal understanding that Support staff hold of non-traditional residents, whom they describe as “like me,” rather than “like everyone else.” This training may help promote meaningful relationships, perhaps benefitting both residents and staff.

During the course of this research, I often reflected on how the Resident Participants might make friends with one another, and I considered adding a Focus Group to provide an opportunity for these men, whose rooms are scattered throughout this very large facility, this chance to connect with persons with similar experiences. The facilitation of peer-to-peer mentorship of younger residents helping others who admitted to the nursing home may establish meaningful relationships between non-traditionally aged persons, and provide meaningful roles, as well. Social Workers could facilitate these connections between residents and possibly meet the blanket goal of “meaningful relationships,” as outlined for so many non-traditionally aged residents.

An additional implication for practice involves working with outside agencies and organizations to foster greater access to community resources, such as activities, shopping, and transportation. All Resident Participants express a desire to shop for specific items, including clothes and food. As Mike shares, while sitting on the porch: “You know, I’m a grown man. A grown man wants a pizza when a grown man wants a pizza. A grown man doesn’t want a pizza when someone decides to give him a pizza.”

Folding in personalized activities may instill a measure of anticipation and

purpose to lives often measured by mealtimes and medicine.

Strengths and Limitations

Strengths

Perhaps, the greatest strength of this study is my experience as an LTC Social Worker, as my experience as an LTC Social Worker in this particular setting, including the pilot study I conducted in the summer of 2018, established my presence as a trusted person who straddled the line between insider and outsider. With few exceptions, my research was accepted by all levels of staff in this setting, including the Administrative staff, who supported this study by providing access to documents, residents, and staff members. Though gatekeepers demanded adherence to governmental regulations and organizational rules, such as encryption of sent and received information, none of the organizational expectations exceeded anticipated barriers outlined in the research proposal. Like the resident participants, I perceived the perceptions of the administration and staff, and intentionally adopted behaviors, including informing regulatory organizations of the study, providing periodic updates to administration, and signing in for visits. My behaviors maintained trust with the facility administrator, Director of Nursing, and Director of Social Services, who welcomed my presence and assisted my efforts over the course of this research.

This level of trust was also apparent as I interacted with the various participants of this study, with all resident participants and most staff openly discussing perceptions and perspectives about the residential experience of non-traditionally aged residents in the LTC setting. Further, observations made in this setting did not appear to be hampered by my presence and after a few initial visits and observations, I was often benignly ignored,

as staff went about their tasks, seemingly unbothered by the process of me looking through documents or taking notes. My observations did not seem perceived as a potential criticism of their work and thus, I think I faded into the background as I observed natural behaviors and interactions of residents and staff.

A second strength is the representation of the Focus Group participants. The men and women who participated in the CNA and Social Work Focus Groups are representative of various ages, education attainments, genders, income levels, races, sexual orientations, and time-in-service. Though perspectives on specific younger residents vary, general perceptions of non-traditionally aged residents fall into two themes: (1) residents are the same, regardless of age and (2) caring for younger residents is time-intensive. These verbal expressions of perspectives often differ from observations of LTC staff, with (1) non-traditionally aged residents receiving less personalized care than older residents, and (2) staff-to-resident interactions with non-traditionally aged residents involve less time than staff-to-resident interactions with older residents.

An additional strength of the study is the purposive sampling of resident participants (Gentles, Charles, Ploeg, & McKibbin, 2015; Yin, 2018), all of whom experienced common characteristics of disadvantage and homogeneity of demographic information, including age and socio-economic status. This homogeneous sampling of a small group of participants echoed Census-based descriptions of younger persons in care and provided a rich description of non-traditionally aged residents in the LTC setting, answering the research questions of this study.

A further strength of the study is the richness of data. I examined this natural setting, using multiple points of data, which revealed the perspectives that passively and

actively affect the experience of non-traditionally aged persons living in the LTC setting. This *life study method*, was described by Cooley (n.d.) as providing rich details leading to natural inferences about similar individuals or situations. Especially rich data was gathered through this study, particularly with the small sample of Resident Participants.

Though findings from case studies are not intended to generalize to target populations, I believe that findings from small studies can speak to particular sets of implications that might be relevant in other residential care settings. By deeply mining the residential experience of this group of men, I was able to understand more about their perspective as residents of LTC. I had depth in the triangulation of this study and was able to find an unexpected pattern – intentional action taken by residents that was perceived by them as an environmental control, influencing the way they were perceived by workers. Multiple interviews over the course of several weeks allowed for the development of trust between me and the Resident Participants. It is doubtful that I could have captured the depth of understanding about how these persons perceive, assess, and respond to perceptions in this closed environment if the study was conducted with a broader focus.

Limitations

All research has limitations. The limitations of this research are foils of the strengths. The first limitation of this study is my experience in this setting. Though this provided access and trust, it also influenced my own perceptions about my observations, which were filtered through prior experience and familiarity. Conducting this research in an unfamiliar site would have layered findings from my pilot study comparatively using another site of research. Case study is bounded, and this study is bounded by this

particular LTC setting, Golden Acres. Context matters. It frames observations and findings; however, context also limits findings to this particular setting, at this particular time. This study is limited by the examination of one site. Though this study is bounded by this LTC setting, a broader design, including multiple sites across multiple locations may more fully examine perspectives of the residential experience of non-traditionally aged persons living in LTC.

A second limitation of the study was the use of only Focus Groups for CNAs and Social Workers. Though data gathered from these groups was important, individual interviews with CNAs and Social Workers may have allowed more open discussion about these participants' perspectives regarding non-traditionally aged residents, which sometimes seemed stifled by group dynamics. Adding personal interviews of CNAs and Social Workers would add a layering of data. Similarly, bringing the Resident Participants together for a Focus Group would add an additional layer of understanding.

A further limitation is the use of purposive sampling for this case research. A larger study, across the broader sampling frame may provide greater diversity among Resident Participants.

Finally, the sample size, Resident Participants ($N = 4$), of this case study may, arguably, be seen as a limitation especially by quantitative researchers for whom generalizing to populations from data is possible. Future, broader studies of the target population of non-traditionally aged residents may offer statistically significant quantitative findings that are generalizable to the broader group.

Further Recommendations for Research

I am dismayed by stories of researchers who enter environments, gather data,

and leave. This approach is, for me, an unattractive methodology. I worked with persons who have limited social connections for the bulk of my adult life, and I believe that ethical work is relational work. If “relationship is the heart of helping people” (Perlman, 1979) and determining “the right thing to do” (Pollard, 2015) is a moral consideration for healthcare professionals, then responsible research involves establishing relationships that incorporate mutual respect and the acknowledgement of interconnectedness between the researcher and participants. I invested time in establishing relationships with the Resident Participants, and they invested in me. I believe my continued visits with these men expand their limited social connections. Ethical considerations admonish me to respect the dignity and worth of individuals (NASW, 2017). Involving these participants in the development, analysis, and dissemination of this study incorporates a practice of relational ethics that respects the interdependency and connected nature of the researcher and the subject (Pollard, 2015).

The growing number of non-traditionally aged residents permanently admitting to LTC supports further research on these persons, their needs, and gaps in policy that fail to address the complexity of care for this vulnerable population. Additional exploration of non-traditionally aged residents, incorporating their voices is necessary to learn more about better ways to holistically address the challenges and barriers faced by this population, including upstream issues of policy. Further research employing case studies, qualitative, and mixed methodologies may facilitate a broader understanding of the residential experience of non-traditionally aged residents of LTC.

Furthermore, additional research about the role of Support staff may demonstrate the value of non-nursing staff in LTC environments. These persons were consistently

observed as attentive and kind to non-traditionally aged (as well as traditionally aged) residents. Understanding more about this group of workers, and how they might be folded into the social world of persons who live in institutional settings, may help provide ways to emphasize the importance of *caring about* – not just *caring for* – persons who are dependent upon others.

Finally, as I anticipate my future research, I find myself drawn to the prospect of exploring non-traditionally aged residents through longitudinal qualitative research. This type of research has been noted as especially important in healthcare (Caruana, Roman, Hernández-Sánchez, & Solli, 2015; Watson, 2015). I believe that a longitudinal qualitative study of non-traditionally aged residents, especially using creative methodologies like narrative or photo voice. Recent research supports these methodologies as empowering for vulnerable persons living in institutional settings (Jaldorn, 2019; Jaldorn & “Deer,” 2017; Woods, Hart, & Spandler, 2019). Such research could reveal a depth of understanding about this group that is missing from current work.

Conclusion

This research builds and expands current literature and contributes to understandings about perceptions of the residential experience of non-traditionally aged residents in the LTC setting and how these perceptions influence actions and behavior. Findings demonstrate that non-traditionally aged residents of LTC perceive themselves as unique individuals that are often lumped together and categorized through negative perceptions by staff, with staff perceiving residents as needy persons whose bad choices make them responsible for their own neediness. Non-traditionally aged residents appear to understand how the LTC staff perceive them, strategizing behaviors to influence better,

and more individualized perceptions among staff members they perceive to have power, to leverage improved delivery of services.



Figure 5.5. Push to exit (English, 2019)

Perceptions from outside the LTC setting also limit the options for these non-traditionally aged residents. Limited community placements are closed to younger persons who are permanently disabled and unable to privately pay for care. Younger persons who have a history of incarceration and/or severe or persistent mental illness are also turned away. For non-traditionally aged persons, admission through the doors of the nursing home entrance comes with little hope for egress, with control extending only to the closed environment of the LTC setting.

Despite these limitations, non-traditionally aged residents develop strategic behaviors to influence perceptions others may hold toward them. Though this study is bounded by the LTC setting, the findings are not restricted to Golden Acres. Persons living with multiple disadvantages are often set apart and away from the larger

community, separated from the *outside world* by barriers, locks, and walls. The men in this case study are so separated; yet, they are not mired by their circumstance. These resilient persons assess their situation, the space, their place, and actively make decisions, employing strategies to improve access to social connections, helping them broker better outcomes for themselves (and, in some cases, others). Goffman (1961) described actions that adjust behavior within institutions in order to meet needs as “make-dos” (p. 209). These make-dos allow persons with limited resources, to make adjustments to thrive in restrictive environments. As Edgar shared: “Girl, I got things to do. I just got to figure out how to get them done... then, I do it.”

Non-traditionally aged residents intentionally use “make-dos” to improve their narrow social world. This was illustrated during a visit I made to the four men, two months after the completion of my data collection. Walter had sent another room-mate on his way and was, once again, living privately. Mike had begun to talk with his Social Worker and discuss moving to another unit where he could, as he put it, “start over.” Leonard, who considered himself to be very politically savvy, returned to his political life, which he had given up during his time with his “adopted family.” He is in the process of protesting against the treatment of migrants at the border by growing out his beard, which is now almost 5 inches long. His Social Worker has care planned his protest into his EMR. Lastly, Edgar, who spoke of his frustration at being denied rehabilitative services, appealed to the facility Administrator and the area Ombudsman, and is now in the process of being evaluated for physical therapy.

The Resident Participants did not appear to be defined by the way they perceived themselves. They did not appear to be defined by the way they were perceived by others.

Nor did they seem defined by the way they perceived others perceived them. Instead, the Resident Participants acted on these perceptions and moved to refine and redefine the way they were perceived, through agentic response. Despite the closed social setting of LTC, the behavior of the Resident Participants appeared to reflect that which was perceived. Like holding a looking glass to a mirror, perceptions influenced an infinite and perpetuating cycle of action and behaviors.

The non-traditionally aged residents of Golden Acres were confined within the LTC setting; however, they did not seem constrained by it. Rather, the non-traditionally aged Resident Participants actively demonstrated resiliency by strategically moving to influence the environment in which they lived and the perceptions of persons who worked there.

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APPENDIX A
IRB APPROVAL



OFFICE OF RESEARCH COMPLIANCE

INSTITUTIONAL REVIEW BOARD FOR HUMAN RESEARCH DECLARATION of NOT RESEARCH

Sara English
College of Social
Work Columbia,
SC 29208

Re: **Pro00085539**

Dear Ms. Sara English:

This is to certify that research study entitled ***Younger Residents Through the Looking Glass: Perceptions of the Residential Experience of Non-Traditionally Aged Residents Living in the Long Term Care Setting*** was reviewed on **3/25/2019** by the Office of Research Compliance, which is an administrative office that supports the University of South Carolina Institutional Review Board (USC IRB). The Office of Research Compliance, on behalf of the Institutional Review Board, has determined that the referenced research study is not subject to the Protection of Human Subject Regulations in accordance with the Code of Federal Regulations 45 CFR 46 et. seq.

No further oversight by the USC IRB is required. However, the investigator should inform the Office of Research Compliance prior to making any substantive changes in the research methods, as this may alter the status of the project and require another review.

If you have questions, contact Lisa M. Johnson at lisaj@mailbox.sc.edu or (803) 777-6670.

Sincerely,

A handwritten signature in blue ink, appearing to read "Lisa M. Johnson".

Lisa M. Johnson
ORC Assistant Director and IRB Manager

University of South Carolina • 1600 Hampton Street, Suite 414 • Columbia, South Carolina
29208 • 803-777-7095

An Equal Opportunity Institution

APPENDIX B
INFORMED CONSENT – RESIDENT PARTICIPANTS

UNIVERSITY OF SOUTH CAROLINA

CONSENT TO BE A RESEARCH SUBJECT

**Younger Residents Through the Looking Glass:
Perceptions of the Residential Experience of Non-traditionally Aged
Residents Living In the Long Term Care Setting**

KEY INFORMATION ABOUT THIS RESEARCH STUDY:

You are invited to volunteer for a research study conducted by Sara J. English. I am a doctoral candidate in the College of Social Work at the University of South Carolina. The purpose of this study is to describe the perspectives of the residential experience of younger persons living in the Long Term Care (LTC) setting. You are being asked to participate in this study because you are a non-traditionally aged person, under the age of 65, and living in the LTC setting. This study is being done at Lexington Medical Center Extended Care and will involve multiple participants, including residents, CNAs, and social workers.

Younger persons are entering LTC in growing numbers, yet policies and procedures overlook this growing population and continue to focus on the needs of older persons who experience multiple chronic conditions (including dementias) and end-of-life issues. Your experience as a resident for many years, will provide a unique look at the life of a non-traditionally aged person living in the LTC setting and how you perceive yourself and how you perceive others perceive you. The purpose of the research is to describe the residential

experience of non-traditionally aged persons living in LTC. The expected duration of participation in this study is three months, using the methods of observation, intensive one-on-one interviews, narrative, and review of artefacts.

There are no expected risks associated with your participation; however, there is a risk to privacy/confidentiality, as these interviews are conducted within the LTC setting. There are no expected benefits for participation in this study; however, the critical lens with which we will be examining your case, has been noted as a means to empower participants.

This form explains what you will be asked to do, if you decide to participate in this study. Please read it carefully and feel free to ask questions before you make a decision about participating.

PROCEDURES:

If you agree to participate in this study, you will do the following:

1. Participate in weekly, intensive one on one interviews regarding your life experiences as a non-traditionally aged resident in the LTC setting. Initial interviews will also ask you to provide demographic information, which will be used in this study.
2. Provide feedback to the researcher to check accuracy of data collection, assumptions, and interpretations.
3. Have your interviews digitally recorded in order to ensure the details that are accurately captured.
4. Give permission for the researcher to review my social services records, including face sheets, BIMS scores, and social service assessments.

DURATION:

Participation in the study involves 3 visits over a period of, approximately, 2.5 months. Each study visit will last about 90 minutes

RISKS/DISCOMFORTS:

Loss of Privacy/Confidentiality: There is the risk of a breach of confidentiality, despite the steps that will be taken to protect your identity. Specific safeguards to protect confidentiality are described in a separate section of this document.

BENEFITS:

Taking part in this study is not likely to benefit you personally; however, as noted previously, you may experience a sense of increased empowerment through the process of telling your story, in your own voice. Additionally, this research may help others understand more about

the lived experience of non-traditionally aged residents in the LTC setting. **COSTS:**
There will be no costs to you for participating in this study.

PAYMENT TO PARTICIPANT:

You will be paid \$25.00, per interview, for participating in this research study. If you do not complete the study.

INCIDENTAL FINDINGS:

If, in the course of this study, information is shared which indicates you to be in danger of being harmed, or harming someone else, the researcher is obligated, as a mandated reporter, to report such information to the appropriate authorities.

COLLECTION OF IDENTIFIABLE PRIVATE INFORMATION:

Collected information will be kept in a secure location and collected data may be used for future studies, beyond the scope of this particular study.

NEW INFORMATION:

If there are significant new findings during the course of the research study that could impact your willingness to continue participating, you will be notified.

CONFIDENTIALITY OF RECORDS:

Unless required by law, information that is obtained in connection with this research study will remain confidential. Any information disclosed would be with your express written permission. Study information will be securely stored in locked files and on password-protected computers. Results of this research study may be published or presented at seminars; however, the report(s) or presentation(s) will not include your name or other identifying information about you.

CONFIDENTIALITY CERTIFICATE:

Certificate cannot be used to resist a demand for information from personnel of the United States federal or state government agency sponsoring the project and that will be used for auditing or program evaluation of agency funded projects or for information that must be disclosed in order to meet the requirements of the federal Food and Drug Administration (FDA). You should understand that a Certificate of Confidentiality does not prevent you or a member of your family from voluntarily releasing information about yourself or your involvement in this research. If an insurer, medical care provider, or other person obtains your written consent to receive research information, then the researchers will not use the Certificate to withhold that information.

RESEARCH RELATED INJURY:

In the event you are injured while participating in this research study, the researcher will immediately notify nursing staff to provide first aid using available resources, and if necessary, arrange for transportation to the nearest emergency medical facility. The University of South Carolina has not set aside funds to compensate you for any injury, complication or related medical care that may arise from participation in this study. Any study-related injury should be reported to the research study team immediately.

VOLUNTARY PARTICIPATION:

Participation in this research study is voluntary. You are free not to participate, or to stop participating at any time, for any reason without negative consequences. In the event that you do withdraw from this study, the information you have already provided will be kept in a confidential manner. If you wish to withdraw from the study, please call or email the principal investigator listed on this form.

I have been given a chance to ask questions about this research study. These questions have been answered to my satisfaction. If I have any more questions about my participation in this study, or a study related injury, I am to contact Sara J. English at (803) 397-7194 or email (sarae@email.sc.edu).

Questions about your rights as a research subject are to be directed to, Lisa Johnson, Assistant Director, Office of Research Compliance, University of South Carolina, 1600 Hampton Street, Suite 414D, Columbia, SC 29208, phone: (803) 777-7095 or email: LisaJ@mailbox.sc.edu.

I agree to participate in this study. I have been given a copy of this form for my own records.

If you wish to participate, you should make your mark below.

Signature of Subject / Participant

Date

Signature of Qualified Person Obtaining Consent

Date

APPENDIX C

INFORMED CONSENT – FOCUS GROUPS

Principal Investigator: Sara J. English, LMSW

Contact Information: sarae@email.sc.edu

Purpose

This study investigates perspectives about younger residents living in LTC settings. As part of this study you will be asked to participate in a focus group and answer structured and open-ended questions. This study will take approximately 60-90 minutes.

Participants' Rights

I understand that my responses will be kept in the strictest of confidence and will be available only to the researcher. No one will be able to identify me when the results are reported and my name will not appear anywhere in the written report. Please do not share other people's identities or responses from the focus group with others to maintain the anonymity of the participants outside of the focus group. I also understand that I may skip any questions or tasks that I do not wish to answer or complete. I understand that the consent form will be kept separate from the data records to ensure confidentiality. I may choose not to participate or withdraw at any time during the study without penalty. I agree to have my verbal responses tape-recorded and transcribed for further analysis with the understanding that my responses will not be linked to me personally in any way. After the transcription is completed, the tape recordings will be destroyed.

I understand that upon completion, I will be given full explanation of the study. If I am uncomfortable with any part of this study, I may contact Dr. Naomi Farber, Chairperson of the Doctoral Committee at the College of Social Work, University of South Carolina at

(803) 777-8816.

I understand that I am participating in a study of my own free will. There are no anticipated risks or benefits from participating in this focus group; however, participants will receive \$25.00 as an incentive for participation in this study.

Consent to Participate

I acknowledge that I am at least eighteen years old, and that I understand my rights as a research participant as outlined above. I acknowledge that my participation is fully voluntary.

Print Name: _____

Signature: _____ Date: _____

Purpose

This study investigates perspectives about younger residents living in LTC settings. As part of this study you will be asked to participate in a focus group and answer structured and open-ended questions. This focus group will take approximately 60-90 minutes.

Participants' Rights

I understand that my responses will be kept in the strictest of confidence and will be available only to the researcher. No one will be able to identify me when the results are reported and my name will not appear anywhere in the written report. Please do not share other people's identities or responses from the focus group with others to maintain the anonymity of the participants outside of the focus group. I also understand that I may skip any questions or tasks that I do not wish to answer or complete. I understand that the consent form will be kept separate from the data records to ensure confidentiality. I may choose not to participate or withdraw at any time during the study without penalty. I agree to have my verbal responses tape-

recorded and transcribed for further analysis with the understanding that my responses will not be linked to me personally in any way. After the transcription is completed, the digital recording(s) will be destroyed.

I understand that upon completion, I will be given full explanation of the study. If I am uncomfortable with any part of this study, I may contact Dr. Naomi Farber, Chairperson of the Doctoral Committee at the College of Social Work, University of South Carolina at (803) 777-8816.

I understand that I am participating in a study of my own free will. There are no anticipated risks or benefits from participating in this focus group; however, participants will receive a catered lunch as an incentive for participation in this study.

Consent to Participate

I acknowledge that I am at least eighteen years old, and that I understand my rights as a research participant as outlined above. I acknowledge that my participation is fully voluntary.

Print Name: _____

Signature: _____ Date: _____

APPENDIX D

RESEARCH TIMETABLE

Action	Estimated Time Frame
Defend Dissertation Proposal	Fall 2018
IRB Application	Winter 2018
Update and Expand Literature Review	Winter 2018
Finalize Interview Protocol	Winter 2018
Select Participants	Winter 2018
Interview One	Spring 2019
Observations	Spring 2019
Review of Documents	Spring 2019
Interview Two	Spring 2019
Focus Group - CNAs	Spring 2019
Focus Group - SWs	Spring 2019
Interview Three	Spring 2019
Field notes and Memos	On-going
Transcription	On-going
1st Cycle Coding	Spring 2019
2nd Cycle Coding	Spring-Summer 2019
Visit BHL archives	May 2019
Draft writing	On-going
Consultation with Chair	On-going
Consultation with Committee Members	As needed
Triangulate findings with participants	Ongoing; Complete: Summer 2019
Final Draft to Committee	August 2019
Share Findings with Organization	July 2019
Defense	August 2019

APPENDIX E

RECRUITMENT FLYER FOR CNA FOCUS GROUP



Looking for CNAs to participate in focus group that focuses on perspectives of Certified Nurse Aides who work in Long-Term Care. Please, contact Sara English for more information:

sarae@email.sc.edu or text to 803-397-7194

This study is part of a dissertation case study and is overseen by the University of South Carolina.

Lunch and a Wal-Mart gift card will be provided.

APPENDIX F

**PROTOCOL FOR SEMI-STRUCTURED INTERVIEWS WITH
RESIDENT PARTICIPANTS**

Interview One

INFORMED CONSENT

DO YOU HAVE ANY QUESTIONS BEFORE WE BEGIN?

- 1.) Tell me about how you came to the nursing home.
- 2.) What do you think are the reasons you came to live here, rather than somewhere else?
- 3.) Tell me about a typical day for you.
- 4.) How do you think you fit in here, at the nursing home?
- 5.) Tell me about your friends/relationships here. Who do you consider to be your friends? Who is special?
- 6.) Tell me about your friends/relationships before you came to the nursing home.
Who was special?
- 7.) How do you see yourself as a resident, here?

Interview Two

DO YOU HAVE ANY QUESTIONS FOR ME?

REVIEW OF DATA AND MEMBER-CHECK

1. How do you think others see you, here? Tell me more about that.
2. How important to you feel? What do you mean?
3. Do you think people know much about your life before you came to Golden Acres?
4. Tell me more about your life before you came here.

Interview Three

DO YOU HAVE ANY QUESTIONS FOR ME?

REVIEW OF DATA AND MEMBER-CHECK

1. What do you think people think about you?
2. What did people think about you before you came to Golden Acres?
3. Tell me what you think people think when they see you coming down the hall?
4. What about friends? Tell me more about that.
5. Who helps you, here?
6. Who can you count on?
7. Tell me more about how you count on people (or not)

APPENDIX G

PRE-FOCUS GROUP SURVEY – CNAs

Hello! You are being asked to complete this brief survey to help assess broad themes regarding younger residents (under the age of 65) who are living in the Long-Term Care setting. The purpose of this survey is to gather general information from social workers, working at this site. This study is approved and supervised by the University of South Carolina.

No identifiable information is attached to this survey and you are not required to participate. This survey is voluntary and anonymous, and you are free to refuse to participate or refuse to answer any questions on this survey without fear without harm or retribution of any kind. There are no known risks to this study; however, the risk to confidentiality is always present in focus groups and you are asked to respect the privacy of what is discussed as we meet. The findings from this survey will be kept private and the intention of the survey is to help shape focus group questions.

The survey questions are broadly based and should take no more than 5-10 minutes to complete. If you choose to participate in this survey, please return to sarae@email.sc.edu, prior to May 2, 2019.

THANK YOU FOR HELPING WITH THIS SURVEY!!!

1. Are you certified? Circle One.
 - a. Yes
 - b. No
2. How long have you worked as a CNA? Circle One.
 - a. Less than 5 years
 - b. 5-10 years
 - c. More than 10 years
3. Do any residents younger than 65 years of age live on units where you are assigned? Circle One
 - a. Yes
 - b. No
4. How many residents younger than 65 years of age live on “your units?” Circle One.
 - a. None
 - b. 1-4
 - c. More than 5
5. In your opinion, are these younger residents more demanding than older residents? Circle One.
 - a. Yes
 - b. No

6. In your opinion, are younger residents dangerous to older residents? Circle One.
- a. Yes
 - b. No
7. In your opinion, are younger residents dangerous to the staff? Circle One.
- a. Yes
 - b. No
8. Thinking about the amount of time you spend addressing the needs of younger residents who live on “your units,” please answer the following... Circle One.
- a. Younger residents require more of my time than older residents.
 - b. Younger residents require less of my time than older residents.
 - c. Younger residents require about the same amount of my time as older residents.
9. Please, feel free to add any comments you might like to share about working with younger residents:

APPENDIX H

FOCUS GROUP PROTOCOL – CNAs

INFORMED CONSENT

DO YOU HAVE ANY QUESTIONS BEFORE WE BEGIN?

INTRODUCE THE RESEARCH ASSISTANT

CONFIDENTIALITY – WHAT WE SAY HERE, STAYS HERE

RESEARCH OVERVIEW

- 1.) Thank you for completing the Survey. All of you indicated that you worked with at least one or more younger residents. I would like to hear what your impressions are about these younger residents.
- 2.) Thank you. What is it that causes these younger people to come to the nursing home? (Say a little more about this)
- 3.) Thank you. As you might remember, the survey asked about younger residents and violence. What are your thoughts on this? (Say a little more about this)
- 4.) Thank you. I am interested in hearing what the typical work day is like for you all.
- 5.) Wow, that sounds like a lot! How do younger residents impact your workday?
- 6.) Thank you. So... one more question. How important do you see your role here, at Golden Acres?

APPENDIX I

PRE-FOCUS GROUP SURVEY – SOCIAL WORKERS

Hello! You are being asked to complete this brief survey to help assess broad themes regarding younger residents (under the age of 65) who are living in the Long-Term Care setting. The purpose of this survey is to gather general information from social workers, working at this site. This study is approved and supervised by the University of South Carolina. No identifiable information is attached to this survey and you are not required to participate. This survey is voluntary and anonymous, and you are free to refuse to participate or refuse to answer any questions on this survey without fear without harm or retribution of any kind. There are no known risks to this study; however, the risk to confidentiality is always present in focus groups and you are asked to respect the privacy of what is discussed as we meet. The findings from this survey will be kept private and the intention of the survey is to help shape focus group questions. The survey questions are broadly based and should take no more than 5-10 minutes to complete. If you choose to participate in this survey, please return to sarae@email.sc.edu, prior to May 2, 2019.

THANK YOU FOR HELPING WITH THIS SURVEY!!!

1. Are you currently licensed as a social worker? Circle One.
 - a. Yes
 - b. No
2. How long have you worked as a social worker? Circle One.
 - a. Less than 5 years
 - b. 5-10 years
 - c. More than 10 years
3. Do any residents younger than 65 years of age live on units where you are assigned? Circle One
 - a. Yes
 - b. No
4. How many residents younger than 65 years of age live on “your units?” Circle One.
 - a. None
 - b. 1-4
 - c. More than 5
5. In your opinion, are these younger residents more demanding than older residents? Circle One.
 - a. Yes
 - b. No

6. In your opinion, are younger residents dangerous to older residents? Circle One.
- a. Yes
 - b. No
7. In your opinion, are younger residents dangerous to the staff? Circle One.
- a. Yes
 - b. No
8. Thinking about the amount of time you spend addressing the needs of younger residents who live on “your units,” please answer the following... Circle One.
- a. Younger residents require more of my time than older residents.
 - b. Younger residents require less of my time than older residents.
 - c. Younger residents require about the same amount of my time as older residents.
9. Please, feel free to add any comments you might like to share about working with younger residents.

APPENDIX J

FOCUS GROUP PROTOCOL – SOCIAL WORKERS

INCENTIVE – WORKING LUNCH

INFORMED CONSENT

DO YOU HAVE ANY QUESTIONS BEFORE WE BEGIN?

INTRODUCE THE RESEARCH ASSISTANT

CONFIDENTIALITY – WHAT WE SAY HERE, STAYS HERE

RESEARCH OVERVIEW

- 1.) Thank you for completing the Survey. All of you indicated that you worked with at least one or more younger residents. I would like to hear what your impressions are about these younger residents.
- 2.) Thank you. What is it that causes these younger people to come to the nursing home? (Say a little more about this)
- 3.) Thank you. As you might remember, the survey asked about younger residents and violence. What are your thoughts on this? (Say a little more about this)
- 4.) Thank you. Social Workers have a unique role in the nursing home. How do you see your role, when it comes to working with younger residents? (Let's talk a little more about that)
- 5.) So... How do younger residents impact your workday?

6.) Thank you. One more question... How do you see your relationship with younger residents who live in the nursing home?